



Medical Record Keeping

Positive health: The passport approach to improving continuity of care for low income South African chronic disease sufferers.

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Prologue

While working in the Michael Mapongwana clinic and the newly commissioned Khayelitsha District Hospital as a community service medical officer, I experienced the overburdening of local facilities by patients from further afield seeking healthcare. Often, these patients present with serious complications after a period of neglectful dismissal of cardinal symptoms, misdiagnoses and treatment complications.

These patients have left behind them a fractured health system and their official medical records. Time and resources are spent on duplication of clinical assessments, biochemical and radiological investigations and subsequent treatment.

Stable patients with chronic conditions such as HIV, hypertension, diabetes, epilepsy and asthma are amongst those affected. Without adequate documentation denoting diagnoses, prescriptions and follow-up plans, cross provincial continuity of care cannot take place, resulting in preventable morbidity and mortality.

While the migrant, peri-urban population epitomises the risks associated with loss of health records, stable populations with chronic diseases face similar problems. Medical records are currently institution specific. Cardboard folders containing an array of written notes, laboratory investigations and referral letters are the main data repository of patients' health. These are stored in archives by assigned folder numbers.

In essence, my focus is on portable medical record keeping for chronic disease sufferers in lower socio-economic groups with the intent on improving their format in a way that is both socially acceptable and technologically viable.

Abstract:

Positive health: The passport approach to improving continuity of care for low income South African chronic disease patients

Research Problem:

The South African health system faces numerous challenges associated with its status as a middle-income developing nation. Wasteful expenditure and poor clinical outcomes arise from inefficient inter-organizational communication of patient information and the lack of a centralized health database.

Research question:

How does the experience of chronic disease patients with their health information inform the development of future health records in low income population groups?

Proposition:

Exploration of patient and health care workers experiences of medical records can inform their future development to enhance continuity of care.

Objectives, methodology, procedures and outcome:

Identification of an appropriate format, technological basis and functional design of a prototype medical record system by means of a phenomenological study conducted through in-depth interviews of patients and doctors in order to improve clinical care. Left and right hermeneutics were used to analyse the data and develop themes.

Findings

Health records play a critical role in the clinics workflow processes, document the patients' management and clinical progress. They are an important intermediary in the relationship between the patient and the facility. Inefficiencies in the paper-based system lead to ineffective consultations, loss of continuity of care and discord between practitioners and patients. Improvement of the records format is required to provide ubiquitous access to health and improve patient health literacy.

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1. Introduction

1.1 South African health context

South Africa is a middle-income nation with racially stratified wealth, health and educational disparities. Causal factors related to this inequality stem from apartheid and its legislation of separate development. This legacy has resulted in a significant proportion of the population unable to reach their full potential and contribute to the nation's success (Mayosi & Benatar, 2014).

The South African health system faces numerous challenges associated with the country's economic status as a developing nation. This transition phase is characterized by the quadruple burden of communicable and non-communicable disease; maternal mortality; under-nutrition and the surge of trauma related morbidity and mortality (Mayosi et al., 2009).

A two-tier health care system serves the South African population since the establishment of a for-profit private sector in the late 1980's. Previously, non-governmental facilities were mission hospitals and occupational health facilities were found largely within the mining industry. The development of the burgeoning private sector has skewed the availability of financial and human resources away from lower income groups and rural areas. Fifteen percent of the population has private medical aid coverage, which accounts for 46% of total health expenditure while 62% of general practitioners and 66% of specialists work in the private sector, increasing the patient load on state health care workers (Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009).

Years of underfunding, mismanagement and neglect has culminated in the degradation of many state health facilities, with those in the Eastern Cape most visibly affected (Mayosi & Benatar, 2014). Systemic health inequalities are found between provinces as well as within metropolitan areas with considerable differences in the provision of health services and resultant mortality and morbidity present (Mayosi et al., 2009).

Aggravating this crisis is the instability created by a poverty-stricken migratory rural

population. To illustrate the point, two million people born in the Eastern Cape live in other provinces, 900 000 in the Western Cape and 500 000 in Gauteng respectively (Statistics South Africa, 2012).

South Africa has the world's largest antiretroviral (ARV) program (Mayosi et al., 2014). Its success has resulted in increased survival rates amongst HIV positive patients. An older population coupled with the premature ageing effects of the condition has led to vascular disease being the leading cause of death in the 50 and above age group (Health Systems Trust, 2014). While HIV and tuberculosis are still prevalent, the epidemiological transition from diseases of poverty to lifestyle-associated non-communicable chronic diseases such as diabetes, hypertension, respiratory disease and cancer, has also occurred, increasing the burden on an already stretched health system. Fragmentation of the health system and reliance on paper-based records make it difficult for patients to achieve continuity of care.

1.2 Research Problem

Health records in the public health sector are predominantly paper-based and are institution specific, with the absence of a population-wide information database. Advances in the provision of services, greater specialization, high staff turnover and large patient numbers contribute to making the current system unequal to the task required to achieve satisfactory continuity of care (Mostert-Phipps, Pottas, & Korpela, 2012). While these records may have been adequate in the past, they no longer suffice in the current clinical environment. Failure to adequately document and communicate patient information can lead to preventable morbidity and mortality in an already vulnerable population.

1.3 Research Purpose

The researcher takes a constructivist approach to explore the experiences of patients and doctors with paper-based medical records to examine their role in the health transaction, the purposes they serve and their potential to be improved for the purpose of enhancing continuity of care and patient empowerment.

1.4 Significance

There is a large body of evidence in the literature supporting the adoption and dissemination of electronic health records (see literature review) in the developed world with local proponents advocating a similar path. The costs of implementation are considerable and necessitate a cautious approach to the development of a contextually appropriate solution. Thus far, there is a paucity of published research on local public sector patient and doctors' experiences and needs of health records. This study aims to explore these propensities.

1.5 Research Question

How does the experience of chronic disease patients with their health information inform the development of future health records in low income population groups?

1.6 Proposition

Exploration of patient and health care workers experiences of medical records can inform their future development to enhance continuity of care.

1.7 Objectives

- Investigate the development of health records focusing on factors affecting their evolution.
- Survey the forms and capabilities of health information systems locally and globally.
- Explore the roles played by health records in the public sector clinic and their efficiency in fulfilling these ends.
- Examine how health records affect the doctor-patient relationship.
- Analyze local end-user experiences of health information systems.
- Identify a set of guidelines by which future health records can be developed.
- Draw conclusions and recommendations based on the research.
- Develop and prototype an innovative health record designed according to the informational needs of the end-user in a contextually appropriate manner.
- Create a business plan to take the innovation to market.

1.8 Key questions:

1. What form do health records take and what roles do they play in the primary level public health clinic?
2. How do users experience health records?
3. How effective are currently used records and is there a need for change?
4. What improvements can be made to health records to serve the needs of doctors and patients?
5. What is the best format for future health records?
6. Are electronic health records feasible for use in public sector clinics?

1.9 Scope and limitations

The research will explore the experiences of doctor and patients attending the chronic diseases club at Vanguard Community Health Centre which serves a lower socio-economic demographic from the Langa and Bontheuwel communities. This includes stable patients with non-communicable diseases such as diabetes, hypertension and epilepsy. Patients with HIV and TB are not included, nor are inpatients, or those with acute presentations. The implications are that findings can only be applied to analogous groups.

1.10 Research Assumptions

Assumptions inherent in the qualitative nature of the study include:

1. Participation by subjects is entirely voluntary, with a sincere interest unmotivated by ulterior motives or incentives.
2. Inclusion into the study is based on the experience of the matter in question, namely health record keeping for chronic disease suffers in the peri-urban public health sector.
3. Responses given by participants in the course of the interview will be honest and candid, giving the researcher an insight into their lives, thoughts and meanings.

1.11 Ethics

The right of research subjects to safeguard their integrity must always be respected. Every precaution should be taken to respect the privacy of the subject, the confidentiality of the patient's information and to minimize the impact of the study on the subject's physical and mental integrity and on the personality of the subject.

(World Health Organization, 2001 p.79)

Ethics plays a fundamental role in research endeavors, especially when dealing with vulnerable populations due to the inherent mismatch in power between researcher and subject (Kvale, 2007; World Health Organization, 2001). The Graduate School of Business's Ethics Committee gave approval for my research to be conducted. Furthermore, conformance to the Western Cape Department of Health's stringent criteria for research was required prior to accessing patients at its facilities. This includes online submission of the following documentation.

- Research proposal/protocol and supporting documents
- Ethics clearance letter
- Annexure 2 (completed) template attached
- Medicines Control Council (MCC) approval
- Proof of registration with the National Clinical Trials Register
- CVs of principal investigator and collaborating researchers
 - (Western Cape Health Research Committee, 2012)

Approval was gained from the City of Cape Town's Health Research Committee for the study to be conducted at Vanguard Community Health Centre's chronic disease club. Informed consent was gained from all research participants prior to commencement of the interview.

With the use of the consent agreement form, I explained the following to the subjects:

1. That they are participating in research
2. The purpose of the research (without stating the central research question)
3. The procedures of the research
4. The risk and benefits of the research

5. The voluntary nature of research participation
6. The subject's (informant's) right to stop the research at any time
7. The procedures used to protect confidentiality

(Groenewald, 2004 p.10)

Emphasis was placed on the voluntary nature of inclusion into the study and that it would not have any effect on their treatment at the facility. This is to prevent patient from 'institutional vulnerability,' which Stark and Hedgecoe (2010) describe as 'people's tendency to feel compelled to participate in research because of the settings in which they have been approached to enroll. This concept does not address participants' sense of hope...but their sense of obligation.'

More challenging however, was counteracting the possibility of 'therapeutic misconception,' or the belief that participation in the study will improve the patient's health (Stark & Hedgecoe, 2010).

While the Helsinki Declaration covers patient rights, protecting the identity of the finite number of doctors working at the clinic more broadly relates to 'local confidentiality' and possible reprisals against perceived whistle-blowing. Bosk (2000) describes 'local confidentiality' as the identification or attribution of (mostly negative) views by participants to their colleagues and comments that it can have negative effects on the social climate long after the completion of the study. Furthermore, Bosk (2000) contends that this effect is prevalent in 'highly literate subjects within one's own culture' (as cited in Stark & Hedgecoe, 2010, p.12).

An unforeseen ethical dilemma I encountered while undertaking research at the facility was navigating requests for advice by junior doctors in the management of their patients. As I regarded this to be in conflict of my role as a researcher an encouragement of the 'therapeutic misconception' I referred them on to their senior colleagues.

2. Literature review

2.1 Introduction

The purpose of this literature review is to inform and contextualize the transition from current practices to future possibilities in order to improve the delivery of healthcare. I begin by grounding the topic with a historical narrative of the development and need for record keeping. Factors leading to the evolution of the form and functionality of medical records are elaborated upon, with the limitations of the paper-based format presented. Personal health records and patients' experiences of records are discussed. Digitization of medical records is discussed within the over-arching framework of information technology and the benefits accrued by implementation to general industry.

Concerns over the creation of 'big data' derived from the documentation and aggregation of patient interactions is viewed through the lenses of medical ethics and law. Local legal and statutory rulings concerning the protection of information are covered in the sections on policy and practice.

The failure of South Africa's public health transition to incorporate health information technology infrastructure is framed within the theoretical models of technological transitions and diffusion of innovations theories.

While the above-mentioned topics impact upon the delivery of healthcare the human aspect of literacy and educational needs are discussed in the context of empowering patient driven continuity of care.

2.2 Record keeping: Pure sense of practice

“Apollonius was ailing for a long time without being confined to bed. He had a swollen abdomen, and a continual pain in the region of the liver had been present for a long time; moreover, he became during this period jaundiced and flatulent: his complexion whitish.” Hippocrates (as cited in Bemmell & Musen, 1997, p. 100)

Medical records are a documentary narrative detailing the interaction of a patient, their health and disease with the broader medical industry. These records contain the evidence of the

patient's bio-psycho-social status obtained by a practitioner from a clinical history and examination, supplemented by data from laboratory and radiological investigations, as well as treatment and ensuing response (Bemmel & Musen, 1997). As medical records document patients past health status and treatment, they are essential for present and future continuity of care.

From the preceding quote ascribed to Hippocrates, medical records sought to further the dual goals of reflecting the course and cause of disease. Furthermore, Bemmel and Musen (1997) observe that the didactic nature of early medicine allowed for documentation in a chronological sequence, telling the story of disease. This we refer to as the time-orientated medical record. An Egyptian papyrus text dating to 1600 BC detailing a surgical procedure is the earliest documented medical record (Gillum, 2013).

Gillum (2013) ascribes the evolution of the medical record from its early didactic form and sporadic use to a more prevalent, physician held case book to the 17th century rise in interest of the natural sciences. Further technological advancements, such as the invention of the stethoscope and other diagnostic instruments led to an expansion of medical terminology to express these findings. The resultant growth in quantitative data further enhanced the need for both structure and recording of clinical information. A transition from documenting the story of the patient, to the clinical findings of the practitioner thus occurred.

The application of quantitative research methodologies and hypothesis testing to case histories by Pierre Louise in the 19th century furthered contemporary understanding of disease process and treatment efficacy. This underscored the value of archiving case records. (Gillum, 2013)

Moreover, insights by A.E. Codman on the potential of case records to coordinate organizational practice and improve quality of care were unprecedented. (Reiser, 1991)

“Heretofore, in hospital organization there has never been a bona fide attempt systematically to fix the responsibility for the success or failure of each case treated. I claim that our record system should enable us to fix responsibility, and that it should be used for this purpose.” (as cited in Reiser, 1991, p.980)

Notwithstanding these advances, the quality of medical records by the turn of the 20th century was seemingly poor with physicians' personal notes being the standard documentary practice. Gillum (2013) puts forward two influences which led to the evolution of medical records: the legal and business fraternities.

By the 1880's, medical records were beginning to be viewed as legal documents for insurance and malpractice claims, increasing physician uptake. Quality of note taking was influenced by, and modelled on legal case history- a diffusion from Harvard Law to the Medical School (Reiser, 1991).

The Mayo Clinic is credited by Reiser (1991) for pioneering the creation of separate files and clinic numbers for new patients admitted to their facility in 1907. This was the beginning of the patient centred clinical record, currently still in use throughout South Africa (Mostert-Phipps, Pottas, & Korpela, 2012).

Apart from the development of the problem-orientated method of note keeping in the 1960's, the paper-based clinical record as devised by the Mayo Clinic in the early 20th century is still ubiquitous in local medical practice. (Mostert-Phipps et al., 2012) Supporting its use, Berg (1996) suggests that the process of writing is a key cognitive component in the transformation of patients' complaints into manageable clinical conditions.

Furthermore, from a mere *aid memoire* of a patient's story, Berg (1996) contends that the medical record has reconstituted itself into an intermediary of collegial interaction, upholder of professional hierarchies, mediator in the doctor-patient relationship, and an active transformer "of the patients' body into an extension of the hospital's routine."

In contrast to these sentiments, Mostert-Phipps et al. (2012) contends that within the context of a fragmented health system with multiple providers, the paper-based medical record, however personal, cannot provide the necessary efficiency to support high quality continuity of care. These records, he maintains, are unfit for the purpose due to their loose structure, illegible content and primitive storage, rendering them inaccessible when required.

"To maintain continuity of care, all healthcare providers caring for a patient should have relevant information that relates to that patient's diagnosis, progress, and management plan, when needed" (Mostert-Phipps et al., 2012).

Continuity of care describes the spectrum of longitudinal interactions that patients have with healthcare providers and institutions extending from the availability of clinical information to relational complexities of empathy, trust and responsibility (Mostert-Phipps et al., 2012).

With evolving chronicity and complexity of co-morbid disease profiles, the paper-based episode-focused system of note keeping has become inadequate. Reasons include:

- Illegible handwriting.
- Fragmented, unstructured folders make it difficult to have an overarching understanding of patients' health and progress of treatment.
- Folders go missing with resultant cost, clinical and medico-legal consequences.
- Continuity of care between facilities is dependent on referral letters, which may not be comprehensive
- Relevant information is not available when attending health facilities for the first time due to relocation or after hour's emergency presentation.

2.3 Use of medical records

From evolution of the form of the medical records, functional enhancement came about with the ascendancy of public health care in the United States in the form of Medicare/ Medicaid and the National Health Service (NHS) in the United Kingdom. Third party involvement took the form of government agencies, courts labour, unions and insurers, apart from research and educational institutions whose influence traditionally shaped the medical fraternity (Reiser, 1991).

Clinical data requirements by these disparate groups met manifold purposes: insurers to audit payments for medical therapy and procedures, courts to arbitrate medico-legal cases, hospital groups to review services rendered as well as planning resource and personnel distribution, researches to create databases for clinical trials, and patients to empower therapeutic choice (Reiser,1991).

These competing influences are argued by Reiser (1991) to effectively change the nature of the clinical record, and by extension, the physician-patient relationship, where the needs of third parties supplant those of the patient.

“When the clinical record is written with a view to establishing claims for third-party billing, justifying the appropriateness of hospital admissions for review boards, or gearing diagnostic conclusions towards diagnostic-related group requirements, its truthfulness can be compromised” (Reiser, 1991).

Raffel (1979) supports this view and advances the sociological perspective that the record “repeats the event but is not supposed to be, in any important sense, itself an event” (as cited in Berg, 1996, p.500)

Far from being a ‘repository of information’ as argued by Dick and Steen (1991), the inclusion of these competing influences moves the record from a representation of reality, to mediating the reality itself (as cited in Berg, 1996)

2.4 Electronic Health Records

Electronic health records are defined by the International Organization for Standardization (ISO) as “a repository of patient data in digital form, stored and exchanged securely, and accessible by multiple authorized users. It contains retrospective, concurrent, and prospective information and its primary purpose is to support continuing, efficient and quality integrated health” (as cited in Häyrynen, Saranto, & Nykänen, 2008, p. 293).

The primary aim of health records is to document patient care. In a review, Häyrynen et al. (2008) cites 25 studies which demonstrated electronic health records to enhance the completeness of documentation. Furthermore, this review also confirms that data found in electronic health records were sufficiently detailed, accurate, relevant and available when evaluated according to the information system success framework formulated by DeLone and McLean.

2.5 Personal Health Records

Personal health records are usually web-based or electronic applications that allow patients to access, document and manage personal health information (Mostert-Phipps, Pottas, & Korpela, 2010). From an examination of the available literature, 'personal health records' supersedes the previously used term, 'patient retained medical records.' By providing access to medical records as well as supplementary health information, these systems enable patient self-management and patient centered care (Archer, Lokker, McKibbin, & Straus, 2011). Patient health records can be owned by the individual or be part of an overarching electronic health record system, with patient access to a customised portal of information and functionality.

As a repository of information, they allow individuals to capture health data from multiple sources over their lifetime, thus allowing them to take a more active role in their own health (Tang, Joan, Bates, Overhage, & Sands, 2006). They are important as patients receive care from many providers with the result that their information is dispersed across multiple facilities and record systems. Tang et al. (2006) argue that fragmented storage and access to essential health information results in the provision of sub-optimal care.

Kerry (2006) supports the view that in the context

Continuity of care is improved by the PHR because of the ready availability of clinical information. Ongoing notes, discharge summaries and prescriptions are carried by the patient in the PHR. In Lesotho, the majority of Primary Health Care (PHC) nurse practitioners and doctors favoured the PHR, called the Bukana, because it improved quality of care through continuity. In Botswana, PHRs facilitated the coordination of care among different units within the health system. (p.16)

In a review of clinical trials involving electronic personal health systems, Archer et al. (2011) found that they improve the access to knowledge of patients and families regarding their health and wellness. Leveraging this access to a wide variety of credible information sources can assist patients in improving their health (Tang, et al., 2006). While personal health

records may be used as a means of facilitating patient engagement, recent reviews (Giardina, Menon, Parrish, Sittig, & Singh, 2014; Goldzweig et al., 2014) have not demonstrated an attributable improvement in clinical outcomes. However, the review by Giardina et al, (2014), demonstrated that patient access to their own records can improve communication with providers, self-management of conditions, as well general satisfaction. Furthermore, studies have found that patient access to their records improved adherence to treatment and knowledge about their own health. Tang et al. (2006) suggest that erudite patients may be more comfortable questioning practitioners and reporting complications. While no clinical benefit has yet been demonstrated, access is unlikely to cause harm to patients (Giardina et al., 2014).

Personal health records can take multiple forms to create the desired functionality. This ranges from stand-alone devices such as smart-cards, CD's, USB drives, or web-based applications which do not connect with other systems to 'tethered system' which act in synchrony to health providers electronic record systems (Tang et al., 2006). Tang et al. (2006) adds that unless patients are highly motivated, they were unlikely to keep their records updated. Furthermore, the reliability of patient entered data is dependent on their level of health literacy and motivation for recording information. So while basic parameters such as height, weight and temperature may be easily entered, physicians may have to be more circumspect in accrediting information upon which clinical decisions are based, such as results of biochemical investigations.

Adoption of personal health records is dependent on the provision of perceptible value to users at a justifiable cost, in a manner that is easy to use and presentation that allows for easy understanding across a wide range of health and general literacy levels (Tang et al., 2006). Research on the uptake of personal health records suggests that while 42% of the American population keeps records of their health, 87% of which is in paper format, only 7% use electronic personal health records (Archer et al. 2011). There is no comparative data on uptake in South Africa. Kerry (2006) however reports that in rural Kwa-Zulu Natal, patients prefer the use of patient held records over their facility specific counterparts. These views are supported by a study undertaken in Lesotho (Henbest, Germond, & Fehrsen, 1995) which maintains that both patients and health staff favour the use of personal health records.

Claimed advantages include more efficient consultations, which affords more time for health education and encouragement of patient ownership.

For successful adoption, end-users need to understand their roles and responsibilities to their own health while the developers understanding of health care processes and workflows is imperative. The mental models of clinicians and patients are important as the personal health records use in coordinating health transactions is viewed by Tang et al (2006) to only be as useful as the understanding and maintenance of health related documentation by patients and providers. Archer et al. (2011) cites that those most interested in personal health records are individuals with disabilities, chronic disease sufferers, frequent healthcare users and caregivers for the elderly.

Adoption and diffusion of personal health records face challenges inherent to all newly introduced technologies. Giardina et al. (2014) state that they are affected by human and organizational complexities, which may either obstruct or advance adoption. Archer et al. (2011) cites inadequate involvement of the intended user during product planning, design and implementation to be linked to adoption failure. These findings are locally corroborated by Pottas and Mostert-Phipps (2013), who recommend further research on establishing user needs for the design and implementation of personal health records.

While creation of a product not suited to the needs of the end-user represent intrinsic components to adoption failure, unforeseen extrinsic factors can also present serious barriers to adoption. End-user factors include lack of trust in the provider and product, limited technological proficiency and technophobia, low health literacy and limited cognitive and physical ability. Resistance to use from physicians who feel that transference of health records to the lay person may threaten their authority and hierarchical position in the provider-patient can be an additional barrier to adoption (Tang et al., 2006). Also of importance, are the effects these health records have on workflow and systems efficiency. Post adoption sustainability of personal health record use involves acceptance, satisfaction and importantly, positive impact on the individual and organization. There is however a paucity of research detailing motivational factors contributing to the ongoing use of personal health records (Archer et al., 2011).

2.6 Patient and doctor experiences of health information and records

“We have decided to allow you to read your notes because: it’s your body and your health. We want to share our decision making with you. We want to break down barriers between the surgery and you. But be careful: there may be things in the notes you are not happy about...No editing, no defacing. No removal from the surgery.” (Baldry, Cheal, Fisher, Gillett, & Huet, 1986 p.596)

The past four decades has seen a growing trend of empowering patients to take a more active role in their health ((Baldry, Cheal, Fisher, Gillett, & Huet, 1986; Giardina et al., 2014; Huvila, Cajander, Daniels, & Ahlfeldt, 2015). Patient access to their health records has been advocated to this end, with legal support to actualized this right (Giardina et al., 2014). At the same time, patients are interested in viewing their records (Delbanco et al., 2012; Fowles, Craft, Kind, Mandel, & Adlis, 2004). Findings by Fowles et al. (2004) suggest that the most common reasons for patients accessing their medical information is to gain a better understanding of their conditions, play a more active role in their health, and find out what their physician said about them. While Munir and Boaden (2001) suggest that while patients are interested in the right to access their records, when given the opportunity, many would not choose to do so (as cited in Huvila et al., 2015). Delbanco et al., (2012) furthers this argument, suggesting that interest rarely translates into actual behaviour. Additionally, in a cross-sectional study by Fowles et al., (2004), findings suggest that patient interest was not related to health status, use of healthcare, education and income. On the other hand, findings by Greenhalgh et al. (2010) on factors influencing individuals to have a summary of care record in the United Kingdom were mostly related to negative health experiences such as adverse drug reactions, loss of consciousness and medical errors. Disinterest in the summary of care record was common in individuals who lacked these experiences (Greenhalgh et al., 2010).

While there is an increase in patients viewing their health information contained in their records, resistance by practitioners is also apparent This resistance is on the basis of concerns regarding increased workload, the possibility of offending patients, creation of unnecessary

patient anxiety from over-interpreting symptoms and worrisome differential diagnoses (Delbanco et al., 2012; Huvila et al., 2015; Woods et al., 2013). In a quasi-experimental trial of providing patients electronic access to their records, Delbanco et al. (2012) demonstrated that in the post-intervention study, doctors' concerns regarding an increase in workload and time spent addressing patients concerns had 'diminished markedly.' In addition, 99% of patients wanted the open notes program to continue and no doctors asked for it to be halted.

A search of the literature demonstrated a predominance of positive experiences by patients with their health information (Baldry et al., 1986; Ball, Smith, & Bakalar, 2007; Delbanco et al., 2012; Fowles et al., 2004; Giardina et al., 2014; Henbest, Germond & Fehrsen, 1995; Huvila et al., 2015; Wibe, Hellesø, Slaughter, & Ekstedt, 2011; Woods et al., 2013). The spectrum of access to clinical information does however range from primary medical notes (Delbanco et al., 2012; Huvila et al., 2015; Woods et al., 2013) to patient held records or summaries (Greenhalgh et al., 2010; Henbest et al., 1995). Positive experiences relate to enhanced communication, increased knowledge and involvement in care and satisfaction. These experiences will be dealt with individually.

Specialization of language is found within professional communities as it enables precise communication and understanding between its members. Huvila et al. (2015) believes that this jargon creates an 'aura of authority' for the work performed which can result in the creation of a barrier between those who can and cannot converse with proficiency. Access to their information can foster patient health information literacy for effective communication (Huvila et al., 2015). A qualitative study (Woods et al., 2013) as well as a quasi-experimental trial (Delbanco et al., 2012) found that patients experience of viewing their medical information improved communication with practitioners. These findings are born out by a more recent review (Kruse, Argueta, Lopez, & Nair, 2015). In addition, Delbanco et al. (2012) found that 'some patients seemed more activated or empowered' as a result and assisted in strengthening the relationship between doctors and patients. Furthermore, participants in a study by Woods et al. (2013) believed that knowledge of their records contents improved the effectiveness of consultations. They described that they felt more prepared for their consultations, knew what questions to ask and were less reliant on health providers for information on their conditions between follow-up visits. Also, they felt more confident communicating with secondary providers who were not involved in the research. Qualitative findings (Henbest et al., 1995; Wibe et al., 2011) suggest that participants were also more willing to take responsibility for transmission of information between different

care givers and facilities. However, two studies reviewed by Giardina et al. (2014) which focused on patient recall as an outcome to accessing medical information yielded mixed results.

Access to personal information contained in medical records was experienced by participants to lead to a perceived increase in their knowledge about their clinical condition and enhance their sense of control of their care (Woods et al., 2013). Narrative research by Wibe et al. (2011) describes participants using the health records as a means of supplementing their subjective experience of illness with a biomedical description to enhance and complete their understanding of disease. However, linked to this was the feeling of loss of control- that their own interests were not being looked after.

A systemic review of patients' involvement in care after accessing their health information showed mixed results (Giardina et al., 2014). However, qualitative studies (Huvila et al., 2015; Woods et al., 2013) described participants desire to be more active and informed after reading their health records. Additionally, participants commented upon enhanced ability to contribute towards shared decision-making and discussions about their health. While particularly insightful, these cannot be quantified.

Eleven studies on patient satisfaction as a primary outcome included in a systemic review by Giardina et al. (2014) yielded mixed results. Eight studies found no significant difference when patients are given access to their medical information via the internet, via USB or on paper, as opposed to no access or only general information, while 3 found moderate improvement in patient satisfaction when receiving a referral letter, copy of physician notes or computerized medical summary. In comparison, qualitative studies (Henbest et al., 1995; Woods et al., 2013) reported patients experiencing enhanced satisfaction after having access to their medical records with Delbanco et al. (2012) adding that doctors perceived patients to be more satisfied after the advent of 'open notes.'

Negative experiences relate to viewing medical records, while less common, are also described in the literature. These include anxiety related to viewing information not usually

disclosed by practitioners, patient concerns about pejorative language, as well as errors and inconsistencies in documentation (Fowles et al., 2004; Woods et al., 2013). Concerns regarding confidentiality and privacy will be discussed in later sections.

Fowles et al. (2004) describe that in a litigious environment with heightened concerns about medical errors, patients are more interested in looking at their records. This is particularly the case when there is a less trusting relationship with healthcare providers. Patient concerns over the accuracy of information contained in their medical records was also found by Wibe et al. (2011). Other negative patient experiences of reading their medical information include not feeling respected as a person, feeling underestimated or unacknowledged and feeling misjudged to have a stigmatised condition (Wibe et al., 2011). These findings were corroborated by Delbanco et al. (2012) who suggests that while few patients reported being concerned or offended by what they read, fear of not knowing what's written may prove to create more anxiety.

2.7 The case for implementation of health information technology

Implementation information technology in the healthcare system can take multiple forms. These include electronic health records, patient portals, telemedicine, physician entry orders and decision support algorithms.

Implementation of information technology (IT) into the last frontier, or as described by Hillestad et al. (2005) 'the world's largest, most inefficient information enterprise' is in the hope of replicating the gains seen in the telecommunications, retail, merchandising and finance industries. IT investment in these industries resulted in 6-8 % annual sector productivity growth in the 1980's and 90's post implementation. Hillestad et al. (2005) attributes 25-33% of this growth to IT. A foreseeable saving by the US health sector of between \$346-813 billion could be accrued based on these estimates.

While benefit is possible from the creation of efficiencies, the financial scale may not be large as in these exclusively for-profit industries. Bower (2005) argues that IT investment in formal economy seeks to establish competitive advantage while development of electronic

health records should primarily be for the dual goals of advancement of patient care, knowledge and research. Also, the substitution of technology for labour force would be moderated by the comparatively skilled capacity of health care workers and the need for human interaction in patient care (Bower, 2005). Although, in a study by Pollack (2007), the implementation of electronic health records in New York City dialysis centres was associated with a 25% reduction in nursing staff (as cited in Buntin, Burke, Hoaglin & Blumenthal, 2003, p.467).

Resource savings would not be immediately apparent. Follow a lag period of increased expenditure required for diffusion of adoption, implementation, and successful process change, resultant efficiencies would be borne out by the double bottom line of enhanced patient outcomes and cost saving (Hillestad et al. 2005).

Findings by Buntin et al. (2011) which surveyed the health information technology (HIT) literature support the benefit of its implementation and use. Of the 154 studies which met inclusion criteria of examining the use of HIT in a clinical setting, 96 (62%) demonstrated an improvement in one or more outcomes, with 142 studies revealing an either positive or mixed positive result.

The use of computerized physician order entry (CPOE) systems built into electronic health records has been shown to reduce adverse drug events (Hillestad et al., 2005). Essentially an electronic drug prescription application, the CPOE alerts physicians to drug interactions and incorrect dosing preventing iatrogenic morbidity and mortality. This helps to reduce unnecessary admissions and litigation. If installed across the United States, Hillestad (2005) claims a \$1 billion annual saving from the prevention of 200 000 adverse drug events. This is an clear example of health IT's cost and life saving potential.

Until recently, there has been very little evidence ascertaining the clinical benefit of electronic health records in a substantive manner. Theorizing as to potential clinical benefits and cautive mechanisms has been carried out (Bower, 2005; Buntin et al., 2011; Häyrynen et al., 2008; Hillestad et al., 2005; Pagliari et al., 2007).

A large physicain survey by King, Patel, Jamoom, & Furukawa (2014) and meta-analysis by Campanella et al., (2015) support the conclusion that the proper implementation of electronic

health records can result in improvement in the quality of patient care. While Poissant, Pereira, Tamblyn & Kawasumi (2005) argued that electronic health records increased physician documentation time, Campanella et al. (2015) 10 years later, using similar methodology (systematic review), concluded the opposite. The authors findings were based on a review of 23 and 47 studies respectively. The more recent positive finding of a decrease in documentation time could be attributed to functional redesign of EHR's around physician workflow.

2.8 The secondary uses of medical data

The secondary use of medical data is well established and has been attributed to the uptake of health information technology in various formats including electronic health records (Coorevits et al., 2013). The documentation of patient encounters in these electronic health records and their aggregation into databases has significant non-clinical application. Coorevits et al., (2013) goes so far as to suggest that “we are on the edge of a golden era of medical understanding.” His views are supported by Safran et al. (2007) and Koh and Tan (2005) who concur that data is an essential part of the medical industry and an ‘asset’ to health organizations.

The introduction of computer science and information technology infrastructure and methodologies into biomedical research, focused on medical data, has allowed for experimentation and trend analysis not previously possible (Coorevits et al., 2013). With these advances, there are however considerable social, political, ethical and legal concerns around privacy of information (Safran et al., 2007) .

Extraction of information and the creation of useable data from primary sources are termed data mining. It has been defined by Koh and Tan (2005), “as the process of finding previously unknown patterns and trends in databases and using that information to build predictive models.”

While more recently applied to health, its use by financial institutions for the creation of credit histories and fraud detection; marketers and retailers for market segmentation; manufacturers for quality control are well known (Koh & Tan, 2005). Ostensibly, these

insights are used to inform clinical and administrative practice with the aim of creating efficiencies and improving patient care.

The pharmaceutical industry pioneered the use of clinical data for drug trials and observational research while working with academic institutions and healthcare organizations. From drug development trials, mining aggregated data sets allows for comparison of treatment efficacy in the general population assisting in creating best practice guidelines (Koh & Tan, 2005).

Furthermore, Rodwin (2010) affirms that population data can now be sourced more affordably, in greater quantity and is perpetually updated making it ideal for research records. Equally important, national, longitudinal data registries would facilitate public health monitoring and coordinate appropriate response (Rodwin, 2010).

A second beneficial and widespread use of data mining is in reforming healthcare management. Applied to population sets, high risk patients with chronic diseases are identified and tracked, enrolled in educational programs and administered the most efficacious treatment, in order to reduce hospitalization (Koh & Tan, 2005).

In contrast to these examples where there is clear value creation for the populace and the medical industry at large, other uses are less meritorious. Whereas data mining to detect fraudulent medical claims, improper referrals and inappropriate prescriptions serves to improve patient care, its use by insurers to restrict care practices infringes on the professional autonomy of medical practitioners (Koh & Tan, 2005).

Likewise, data mining of healthcare transactions by groups such as the Customer Potential Management Corp to create utilization indices for identification and promotion of non-clinical profit making services is equally ethically questionable (Koh & Tan, 2005).

The pharmaceutical industry has exploited this technique from the 1950's, tracking physician prescription patterns for the purpose of creating targeted marketing campaigns to influence choice of treatment. This under the guise of evidence based practice. In fact, physician identification information was sold by the American Medical Association (AMA) who conducted the Fond du Lac marketing study investigating the influence of pharmaceutical

advertising. This profound conflict of interest or, ‘mutual benefit’ as it was termed, between a regulatory body and industry, came full circle with the AMA encouraging pharmaceutical firms to advertise in its journals (Rodwin, 2010).

2.9 Data markets and ownership of health information

The secondary use of information by the health and affiliated industries has led to the creation of patient data markets. Trading of non-anonymized patient and physician information has been documented by the American Medical Informatics Association (AMIA) as a widespread practice, undertaken by the public and private sectors without the knowledge or consent of patients and providers (Safran et al., 2007).

The conciliatory tone of this white paper written by Safran et al. (2007) on the creation of a ‘national framework for the secondary use of health data’ may partly be due to sponsorship by companies such as GlaxoSmithKline, Lockheed Martin, and Pfizer.

Certainly, Rodwin (2010) describes the extent of collaboration between managed care organizations and pharmaceutical companies in the commoditisation of patient records as a ‘multibillion dollar industry’.

IMS, the largest of the medical information organization’s (MIO) brokers the acquisition and sale of patient data in a 100 countries (Rodwin, 2010). Promoting itself as ‘a leading global information and technology service company’, IMS processes 55 billion healthcare transactions annually from 100 000 data suppliers for 5 000 clients (<http://www.imshealth.com>).

"[a]chieving a favorable endorsement from healthcare authorities is critical to ensure that new innovations reach the market and patients more quickly and are incorporated into appropriate guidelines of care." (<http://www.imshealth.com>)

Besides the inherent conflict of interest arising from these third parties influencing medical practice, the flagrant use of patient information obtained by “pressuring or coercing patients to data disclosure” is ethically disquieting (Safran et al., 2007).

The transformation of medical records from personal aid memoire to a saleable commodity has led to questions of ownership and property interests. Whoever owns the data will benefit from its sale. Indeed, institutions with medical, billing and prescription information sell de-identify data encrypted with restriction of use technology as it were private property. While patient records are the physical property of physicians and hospitals, current legislation does not cohesively define ownership of data (Rodwin, 2010). “Just as an individual can own a book, but not the intellectual content printed in it, providers own records but not the patient data itself” (Rodwin, 2010).

Arguments for and against both public and private ownership of data while important, are out of the scope of this review. Broadly however, they involve monopoly formation and restriction of access to competing interests. Indeed, patients are assumed to accrue the benefits in the form of evidence based practice (Rodwin, 2010).

Privatization of patient data into a derivatives market is due to legislative space between insurance and copyright law. The US Health Insurance Portability and Accountability Act of 1996 (HIPAA) does not protect personal health information by groups not covered in its framework.

2.10 Privacy and confidentiality

2.10.1 Information Privacy

Privacy of information is conceptual branch of general privacy which has philosophical, sociological, psychological and legal influences. While its origins may be Hippocratic in nature, its contemporary prominence parallels the growth of information technology. A succinct definition of general privacy is “the right to be left alone” by Warren and Brandeis (as cited in Smith & Dinev, 2011, p. 994).

A more focused definition of information privacy is, “the ability of individuals to control the terms under which their personal information is acquired and used” by Culnan and Bies (as cited in Smith & Dinev, 2011, p. 994).

In the context of medical records, Rindfleisch (1997) defines privacy as, “the right and desire of a person to control the disclosure of personal health information.”

While medical records contain harmless information such as age, blood pressure and weight, disclosure and dissemination of sensitive information detailing psychiatric illness, HIV status and substance abuse can result in discrimination, social embarrassment and uninsurability (Rindfleisch, 1997).

The rapid disseminative property of internet-based electronic health records is both its greatest advantage and cause for concern when compared to paper records. Terry and Francis (2007) corroborate this, citing a study by the California HealthCare Foundation which found that 67% of Americans have concerns regarding the privacy of their health records, when in electronic format. The importance of these concerns cannot be underestimated: Terry and Francis (2007) maintain that cost and perceived lack of confidentiality can prevent the successful implementation of a national electronic health record.

Lack of trust in the systems’ ability to protect information would lead to patients providing misleading or incomplete information, circumventing or entirely avoiding accessing healthcare. In the above-mentioned study by the California HealthCare Foundation, 12.5% of respondents acted in a manner that could compromise their health for the sake of protecting their privacy (Terry and Francis, 2007). These actions include not seeking medical care and testing; paying out of pocket to avoid insurance claims; and asking health workers to change their diagnoses.

Ethical constructs underlying this discourse are the juxtaposition of autonomy related privacy rights with distributive justice. The autonomy of the patient to disclose information with the proviso of confidentiality is being eroded by the notion of the supremacy of longitudinal health data collection for industry and cost benefit (Terry and Francis, 2007).

Findings by the Hopkins Group indicate that while many patients would not agree to have their records used for secondary purposes without separate consent and 34% felt their use to be completely unacceptable, other studies found when actually asked, the ‘overwhelming majority’ of patients agreed to consent (Terry and Francis, 2007).

Seemingly, the context and process of empowering patients to make informed consent is crucial to gain trust and buy-in for nascent EHR systems. Since the alternative would be the perception of the EHR as a governmental surveillance or ‘big brother’ tool (Terry and Francis, 2007).

A qualitative study performed in Lesotho found that healthcare workers were more likely to be concerned about confidentiality than patients themselves (Henbest et al., 1995).

I have thus far addressed information privacy concerns within the context of institutional misuse. Unauthorized access to records by breaches in security is another cause of public apprehension. These can take various forms: from accidental disclosure of information within collegial circles, to insider curiosity of health workers abusing their privilege of access for personal gain, searching for information on family, friends, colleagues and celebrities (Rindfleisch, 1997).

In 2009, Prime Minister Gordon Brown’s medical records were accessed by a doctor without valid reason creating a media scandal (Aitkin, 2009).

Furthermore, access and release of information for the sake of profit or malicious intent is another significant concern for both paper and electronic records (Rindfleisch, 1997).

Whereas security breaches do occur with paper records, the potential magnitude of the threat posed by digitization is significant because of decentralized access in the form of hacking, and ease of dissemination. (Myers, Frieden, Bherwani, & Henning, 2008)

2.10.2 Protection of information: Policy

Protection of medical information in South Africa is covered by the Protection of Personal Information Act of 2013 (POPI) and the National Health Act (Act No. 61 of 2003) as well as stipulations by statutory authorities such as the Health Professions Council of South Africa. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) fulfils a similar role in the USA.

POPI affects all organizations which process personal information in the public and private sector. In the health context, this may be for the provision of a service which legitimately serves the patients best interest (Gillepsie, 2013). In comparison, the HIPAA has little jurisdiction over public entities in the USA (Myers et al., 2008).

Furthermore, POPI places the onus of responsibility for the protection and security of information on the party which collects it, advocating the implementation of reasonable technical and organizations measures (Gillepsie, 2013).

POPI also addresses the secondary use of information which it terms 'processing.' This term comprehensively cover third parties who "collects, receives, records, organises, collates, stores, updates, modifies, retrieves, alters, uses, disseminates, distributes, makes available, merges, links, degrades, destroys or erases personal health information"(Dinnie & Malherbe, 2009).

Under the Act, personal information may only be processed with the consent of the 'data subject' with information provided to them on the reason for collection, its use and possible recipients (Dinnie & Malherbe, 2009).

In cases where processing is outsourced, it is still the responsibility of the primary collector of information to ensure that third parties comply with the conditions of the act, with noncompliance constituting an offence (Dinnie & Malherbe, 2009). Indeed, failure to comply with provisions of the act can lead to civil claims for payment of damages, criminal prosecution with a maximal sentence of 10 year imprisonment or R10 million fines, or both, if convicted (Gillepsie, 2013).

Altogether, the South African legislative framework and statutory bodies are adept in protecting health information privacy.

2.10.3 Protection of information: Practice

From a patient perspective, the most effective means of ensuring privacy of information is by not having it recorded into an interoperable system from the outset, keeping information within the silo of individual providers. Terry and Francis (2007) cite a Markle Foundation report recommending an opt-in policy to this effect. Alternatively, patients could specify the type of information to be withheld or released into the larger system. For example, the exclusion of information pertaining to psychiatric illness, treatment for sexually transmitted diseases or HIV testing could be the clause by which patients' opt-in to the system.

Allowing this autonomy would compromise the veracity of records and decisions made based on incomplete information, but may improve uptake (Terry & Francis, 2007). This finding is supported by Greenhalgh, Robert, Macfarlane, Bate and Kyriakidou (2010) who point out that the transition from an opt-out to opt-in consent policy led to an increase in the adoption of shared electronic records in the UK.

While there are valid concerns regarding the rapid disseminative quality of electronic health records, the implementation of technological tools derived from cryptographic and distributive systems research has created a security advantage not found in paper-based patient records. (Rindfleisch, 1997)

Once information is uploaded onto a central server, the three goals of security are the maintenance of their confidentiality, integrity and availability (Fernández-Alemán, Señor, Lozoya, & Toval, 2013).

A comprehensive literature review of normative privacy and security features of electronic health records has been performed by Fernández-Alemán et al., (2013). Without going into the technical detail, I will highlight three principles which are affirmed by Myers et al. (2008) to be of importance. These are authentication, authorization and auditing.

Authorization is the process of establishing the user base and the type of access that should be granted or withheld. For example, while doctors may have full access to medical records, pharmacists, admin clerks and lab technicians would have access only to information pertinent to their roles. Implementation in this case is based on hierarchical cryptography and may be enforced by patient activated privacy policy managers. In the case of emergencies, access restrictions may be bypassed to save patients' lives (Fernández-Alemán et al., 2013). Authentication is the means by which users prove their identity to the system. Username and password creation is the most common authentication mechanism followed by digital signature schemes (Fernández-Alemán et al., 2013).

Auditing of electronic record log- in data is a widely used practice to prevent illegal and improper access. While viewed as a security tool, Greenhalgh et al. (2010) reports that fear of surveillance deterred physicians from using summary of care records in the UK.

2.11 Health information technology and South Africa: electronic health record transitions

The identification and prioritization of information technology within the South African public health sector took place in late 1990's. The White Paper for the Transformation of the Health System's analysis recommended the development of a National Health Information System (NHIS) on the basis that existing systems were fragmented, uncoordinated and inadequate: "It is anticipated that new attitudes and tools will have to be developed to improve the collection and use of data for the effective management of available resources" (as cited in Masilela, Foster, & Chetty, 2013).

On the impetus of this policy document, a R134 million hospital information system was commissioned in the Limpopo with the hope of implementation across 42 facilities. Utilizing 2.5% of the provinces health budget over 3 years, the project did not proceed as planned. Cited as a cautionary tale in the information technology non-adoption literature, the project was a dismal failure due to disparate issues ranging from power surges from the local bakery causing hardware damage, to differences in expectations between developers, commissioners and end users (Littlejohns, Wyatt, & Garvican, 2003) . This foray into health information technology proved to be a costly lesson for one of South Africa's poorer provinces.

While efforts are being made to expand the use of health information technology within the public health sector, fragmentation and incoordination persist. Masilela et al. (2013) cite the presence of 42 different health information systems throughout the country without interoperability. The roll-out of a national electronic health record has still not been achieved.

Ratification of the World Health Assembly's Resolution 58.28, 'to promote equitable, affordable and universal access' to the benefits of health information technology, by the South African government has led to the formation of the National eHealth Steering Committee. This group has developed a comprehensive eHealth Strategy to inform future investment in this field.

The eHealth Strategy aims to prioritize and co-ordinate future health technology initiatives in South Africa. It seeks to take an incremental approach to infrastructure development, enhanced connectivity and building basic information technology literacy to build the confidence of health professionals and patients (Department of Health, 2012).

A landscape analysis of health information systems in developing nations funded by the Bill and Malinda Gates Foundation classified eHealth maturity into 5 stages of sophistication (Department of Health, 2012). In this classification scheme, paper-based systems for collection health indicators corresponds with stage 1, while a 'fully comprehensive and integrated' national health information system is stage 5. The report placed South Africa at stage 3 overall, 'migration of traditional district health information systems to electronic storage and reporting.' However, variation between individual districts range between stages 1 and 4 (Department of Health, 2012).

Examples of successful national systems are the District Health Information System which records information from facility-based services and community-based campaigns, the National Electronic TB Register which monitors cohorts of TB patients and the Western Cape Primary Healthcare Information System (Department of Health, 2012).

Supporting the transition to a national electronic health record are the Department of Health's (2012) National Health Insurance (NHI) scheme and Western Cape Department of Health's (2014) 'Healthcare 2030' strategic policy document:

Comprehensive record keeping, access to medical records, efficient transfer of medical information between health care professionals and adequate provision of suitably skilled staff are essential to ensuring that patients receive a continuum of care. Advances in technology will enable these requirements. (Western Cape Department of Health, 2014, p.30)

2.12 Technological Transitions Theory

The poor uptake of electronic health records in the South African context and the persistence of paper records 18 years after initial implementation of new strategic direction can be framed within the context of Technological Transitions Theory.

As a nascent theory within the broader configuration of innovation science, technical transitions is an interdisciplinary field combining aspects of history, economics, ecology, sociology, political and governance studies as well as psychology.

Technological Transitions Theory expounded by Geels (2002) describes innovations which result in 'major technological changes in the way societal functions are fulfilled' resulting in a shift to new socio-technical systems. These systems or 'regimes' are the established status quo made up of semi-rigid rules and normative processes by which 'actors' co-ordinate activities, which in themselves perpetuate the regime. Giddens (1984) earlier described these

regime rules as ‘both medium and outcome of actions’ (as cited in Geels, 2011). As described by Geels (2002), “regime rules are cognitive routines and shared beliefs, capabilities and competences, lifestyles and user practices, favourable institutional arrangements and regulations, and legally binding contracts.” Rotmans and Loorbach (2009) define it more simply as a conglomerate of embedded structure, culture and practice.

Regime lock-in and institutionalization of entrenched interests are theoretical reasons furthered to explain the slow process of change (Rotmans & Loorbach, 2009). In order for innovations to gain purchase, reconfiguration of the linkages holding the incumbent regime in place needs to occur. Rotmans & Loorbach (2009) cites the inability to overcome faulty regimes as system failures. Successful reconfiguration on the other hand, while appearing to be revolutionary, may in fact be due to the gradual encroachment and application of incremental changes leading to a new technological trajectory (Geels, 2002).

The multi-level perspective (MLP) is a theory within the overarching framework of technological transitions. It is used to describe the dynamic state of complex relationships between three levels: the niche, socio-technical regime and socio-technical landscape.

While the regime level is a primary concept from which the niche and landscape are derived and transitions defined, the niche plays a fundamental role in its origination and proliferation (Geels, 2011). The niche is an emergent structure formed by agents who deviate from the regime (Rotmans 2009). These structures may be protected from the market through the creation of special conditions such as subsidies and alignment of interest between different groups of actors (Geels, 2002; Rotmans & Loorbach, 2009). Forming the local level of innovation processes, niches may progress to form new regimes if supported by the broader socio-technical landscape. This landscape includes independent variables which influence innovation processes but are not reciprocally affected in the short to medium term (Markard & Truffer, 2008).

Transitions are described by Geels (2011) as ‘moot fire’ due to the ‘smouldering below the surface’ nature of innovations. Breakthroughs into the market are broadly theorized to occur once sufficient internal momentum is gained by niches and changes in the landscape pressures the regime into accommodating the innovation.

While there are multiple patterns to explain technological breakthroughs from niche to regime level, I have selected two to discuss further based on relevance to health information technology. The wider transformation route is put forward by Geels (2005) to describe a process in which multiple problems in the form of changes in ‘policy, user preference, technology, infrastructure, culture’ results in configurative loosening within the regime or landscape. This regime loosening stimulates actors to experiment with new technical options, potentially breaking thorough from the niche to create a new socio-technical regime. This theory highlights transformative potential in medical record keeping from the constraints of the paper-based format to technologically enabled alternatives.

The second pattern within the multi-level perspective framework applicable to health information technologies potential to break through from niche to regime is the fit-stretch model. As a slowly transitioning model, early iterations of new technologies conform to the existing regime in both form and function. Over time, technological advancement leads to new forms while new functionalities are guide by user experience (Geels, 2005).

Enterprise Content Management (ECM) developed by Datacentrix (Pty) Ltd is an example of the stretch-fit model (Weeks, 2013). Currently in use at Tygerberg Academic and Khayelitsha District Hospitals in the greater Cape Town area, it is a hybrid system merging functional features of paper and electronic records. Primary generation of paper-based records continues with electronic capture creating a disseminated, accessible document repository. New technology is implemented to augment rather than replace existing infrastructure conforming to the complexity derived principle of ‘radical change in incremental steps’ (Rotmans & Loorbach, 2009).

Geels and Schot (2007) compare niches and regimes to have

“similar kinds of structures, although different in size and stability. Both niches and regimes have the character of organizational fields (community of interacting groups). For regimes, these communities are large and stable, while for niches they are small and unstable. Both niche and regime communities share certain rules that coordinate action. For regimes these rules are stable and well-articulated; for niche innovations, they are unstable and ‘in the making’ ” (as cited in Markard & Truffer, 2008 p. 606).

In the South African health context, the development of electronic health records can be seen as niche formation within the public-health sector paper-based regime. The landscape contains the greater spectrum of political, economic and health influences as informed by policy and regulatory framework.

While technological transitions theory and the multi-level perspective provide a clear lens through which the creation and dissemination of electronic health records can be viewed, this global perspective does have noteworthy shortcomings limiting its practical use.

Geels (2005a, p. 365), while being a strong proponent of these respective theories, acknowledges the literary preponderance towards viewing technology as an artefact, isolating it from important societal and cultural contributions necessary for its evolution (as cited in Genus & Coles, 2008, p.1440).

The bias towards niches requiring ‘protected spaces’ from an unfavourable regime is also debatable. Kemp, Scot and Hoogma (1998) comment that innovations would be valued and easily adopted, if they provide a good societal fit to be incorporated within the established regime.

Shove and Walker (2007) have criticized the ‘voyeuristic nature’ of the multi-level perspective citing its inability to deal with the circumstantial reality of the transition in question (as cited in Genus & Coles, 2008, p.1442). It would appear that these constructs provide a retrospective mould through which most technological innovation narratives can be cast.

Consequentially, Genus and Cole (2008) observe that transitions theory and the multi-level perspective’s contribution to innovation studies can be limited to providing a heuristic by which technological trajectories can be understood.

2.13 Diffusion of Innovation Model

While Technological Transitions Theory provides a useful starting point from which innovative trajectories can be viewed, Diffusion of Innovations Theory is perhaps positioned at a more suitable level of abstraction for practical implementation purposes.

Whilst there are a plethora of frameworks theorizing the complex processes of adoption and implementation of innovations within organizations and societies, in a systematic review, Wisdom et al. (2013) identifies diffusion of innovations theory as developed by Rogers (1995) and supported by Greenhalgh, Robert, Macfarlane, Bate, & Kyriakidou, (2004) as comprehensive and useful.

“Although citrus juice was shown effective in preventing scurvy in 1601, the British merchant navy did not introduce citrus juice into sailors’ shipboard diets until 1795, nearly two centuries later.” (Mosteller, 1981, p.313)

The concept of diffusion of innovation theory is derived from the observation that new ideas and proven concepts are initially adopted at a slow pace relative to the perceived benefit derived from their potential application (Rogers, 1995).

The theory seeks to fill the gap found across disciplines between knowledge creation and practical implementation. Diffusion is defined by Rogers (2005) as, “the overall spread of an innovation, the process by which an innovation is communicated through certain channels over time among the members of a social system.”

The development of the theory came with analysis of broad diffusion literature by innovation scholars. An ‘emerging technology perspective’ on the diffusion of diverse yet isolated innovations ranging from agricultural practices to fertility control methods and health promotion exercises has been described by Rogers (2005). Synthesis of the dynamics affecting these innovative processes into broader trends by Rogers (1962, 1983, 1995, 2003), Strang and Soule (1998), Wejnert (2002), and Greenhalgh and colleagues (2004, 2005) has led to the development of cross-disciplinary theory building (as cited in Oldenburg & Glanz, 2008 p.315). While Rogers (2003) reports that there are 5200 publications on diffusion of

novel innovations, the majority can be located within the research traditions of rural and medical sociology, marketing and management, communication, and public health (Rogers, 2003). Rogers diffusion of innovations theory is underpinned by these contributory fields (Greenhalgh et al., 2004; Oldenburg & Glanz, 2008).

Adoption of innovations is theorized to take place at a relatively slow rate during the initial diffusion process. A positive interaction with the innovation by early adopters would lead them to share their experiences with potential adopters leading to diffusion of the innovation. Rogers (1995) describes this process as following a sinusoidal curve with a slow initial phase followed by acceleration and development of critical mass. Subsequent levelling off of growth takes place once fewer individuals or organizations are left to adopt. This process has been popularized by Malcolm Gladwell's book, *Tipping Point*.

Whereas transitions theory places novel technology into a niche to changes the socio-technical landscape, diffusion of innovations model can be more useful in guiding the planning and successful application of an electronic health record in South Africa. Furthering the assertion that while some innovation are rapidly diffused, others are only partially adopted and subsequently abandoned or have no success at all, the diffusion of innovations model provides three characteristics to explain these outcomes. (Rogers, 1995)

2.13.1 Attributes of innovations needed for diffusion

Relative advantage is the first attribute cited by Rogers (1995) that an innovation needs to fulfil in order to successfully diffuse. It is defined as “the degree to which an innovation is considered better than the idea that it is superseding” (Rogers, 1995). While being an important characteristic, Denis et al. 2002; Fitzgerald et al. 2002; and Grimshaw et al. 2004 maintain that it does not guarantee successful adoption (as cited in Greenhalgh et al., 2004).

Compatibility of the innovation with existing organizational work processes, values and norms is a second element put forward by Rogers (1995) for successful diffusion and adoption to take place. Aarons et al. 2011; Gallivan, 2001; Mendel et al. 2008; Solomons & Spross, 2011 affirms initial cultural compatibility to be critical to further the pre-adoption negotiation as well as successful implementation phases of innovations. In the societal

context, the importance of culture as a barrier to adoption of public health programs cannot be underestimated. Haider and Kreps (2004) comments that understanding the rationale behind these underlying societal norms may assist developers to assuage entrenched fears and misconceptions early on in the diffusion process thereby circumventing potential barriers to adoption.

Whereas relative advantage and compatibility are viewed to enhance diffusion processes, conversely the perceived complexity of an innovation is related to reduced uptake. Rogers (1995) defines complexity as “the degree to which an innovation is considered as difficult to understand and use.”

Similar to the Stretch-fit Model of Technological Transitions Theory, Greenhalgh et al. (2004) argues that by breaking the innovation down into smaller parts and staggering the adoption process so that implementation takes place incrementally, the drawback of complexity can be reduced. Rogers (1995) cites ability to trial and observability as two other features required for adoption to take place.

Despite the prevalence of diffusion of innovation nomenclature in the general public sphere with terms such as ‘early adopters’ and ‘laggards’ being ubiquitous, Greenhalgh et al. (2004) view individuals to be dynamic actor and active participants. This contrasts with Rogers’ (1995) taxonomy of individuals and organizations as being Innovators, Early Adopters, Early Majority, Late Majority, and Laggards with generalized characteristics pertaining to the groups.

Greenhalgh et al. (2004) contends that people are “not passive recipients of innovations’. Rather (and to a greater or lesser extent in different persons), they seek innovations, experiment with them, evaluate them, find (or fail to find) meaning in them, develop feelings (positive or negative) about them, challenge them, worry about them, complain about them, “work around” them, gain experience with them, modify them to fit particular tasks, and try to improve or redesign them—often through dialogue with other users.”

Bricolage, as defined by Levi-Strauss (1967) is an example of this participant-derived development of innovative solutions through recombination and transformation of existing resources. Di Domenico et al (2010) put forward that ‘it represents the resourcefulness and

adaptability frequently demanded within this field of entrepreneurship as ‘bricoleurs’ develop novel combinations of ideas, opportunities, and organizations.’

Additionally, Fuglsang (2010) cites the dynamism of bricolage as an adaptive behaviour by actors to unforeseen challenges and events which results in skills building and routine expansion. While the results may not be radical, Fuglsang (2010) advocates that is positively impacts upon the development of services.

2.14 Local health landscape

Primary care services are provided by medical officers, nurses and allied health workers and forms the point of entry into the health system (Dookie & Singh, 2012). The Western Cape Department of Health (2014) describes them as a ‘comprehensive range of curative and preventative services...provided with a complementary capacity for rehabilitative and palliative care.’

These services aim to respond to the health needs of communities by means of inter-sectoral collaboration with, and support by district and tertiary level hospitals. It is envisioned that 90% of patient encounters will take place within primary health clinics and district level hospitals with emergency medical services facilitating the transition between levels of care. (Western Cape Department of Health, 2014).

Locally, the provision of these services is the responsibility of both the Provincial Department of Health and the City of Cape Town (Mash, Govender, Isaacs, De Sa, & Schlemmer, 2013). The Cape Town metropolitan health services are divided into four substructures, with further division of each into two subdistricts. Separate management teams are responsible for individual substructures. Altogether, there are 45 community health centres within the metropole. Community Health Centres employ a facility manager, who, together with senior clinicians, are responsible for clinical governance (Mash et al. 2013).

Historical fragmentation and health system inefficiency can be partly attributed to the legacy of apartheid (Dookie & Singh, 2012; Kautzky & Tollman, 2008). Furthermore, Kautzky and Tollman (2008) maintain that “the system was seriously lacking in geographic coherence, with overlapping city, district and provincial health authorities and limited national scope to reconcile gaps or duplication in service provision (p.23).”

South African health systems reform has been undertaken with realignment of individual

health departments' strategic policies and organizational structures to those of the National Department of Health (Kautzky & Tollman, 2008). The sanctioned vehicle of implementation of this primary care reform is the district health system (Dookie & Singh, 2012).

Ongoing failures in health service delivery have a multifactorial etiology, including historical discrepancies in funding, burden of disease, bureaucratisation and poor co-ordination between progressive levels of care (Dookie & Singh, 2012). Compounding these challenges, the South African government cites cost escalation in the booming private health sector to result in 'financial resource misalignment' and 'maldistribution of human resources,' impeding the progress of public sector reform (Department: Planning Monitoring and Evaluation, 2017).

A key component of health sector reform is the improvement of the quality of services provided. A 2012 audit of all 3880 public health facilities led to the development of the 'Ideal Clinic' initiative which seeks to co-ordinate national improvement in service delivery in accordance with the Office of Standards Compliance. It is expected that this institution will encourage innovation to improve the quality of healthcare in South Africa (Health Systems Trust, 2014).

This audit, the Ideal Clinic initiative and promulgation of the Office of Standards Compliance formed key components in the first phase of the 14 year rollout of the National Health Insurance (NHI) financing system (Department: Planning, Monitoring and Evaluation., 2017).

The Department of Health (2017) asserts the NHI's aim is to 'pool funds to actively purchase and provide access to quality, affordable personal healthcare services for all South Africans based on their health needs, irrespective of their socioeconomic status' (p. 3).

Planning and implementation of the NHI subscribes to the guiding principle that healthcare is a 'social investment and therefore should not be subjected to market forces where it is treated as a normal tradable commodity' (Department: Planning, Monitoring and Evaluation, 2017, p.2).

The second phase of NHI rollout expected to commence in 2017/2018 includes its formal legislation, establishment of the NHI fund, and importantly, population registration with the Department of Home Affairs' smart identification system (Department: Planning Monitoring and Evaluation, 2017).

2.15 Health literacy

The previous sections have dealt with contemporary topics of techno-centric advancement as a means of improving the health records capacity to further continuity of care. Kickbusch (2001) argues that the fundamental social, health and economic constraints affecting the worlds' poor cannot be solved by information technology alone. Furthermore, Kickbusch (2001) states that education is needed to develop patient competencies and coping mechanisms that will improve their health and quality of life. In addition to education, and with the increased prevalence of lifestyle diseases and the stabilization of HIV from life threatening to a chronic disease, Ishikawa & Yano, (2008) argue that successful disease management is reliant on patient participation in the health care process. In addition, there is a sizeable body of evidence to suggest that patients are keen to learn more about their clinical conditions (Ishikawa & Yano, 2008). While health care workers have traditionally been the primary source of health information for patients, alternative resources are now more widespread and easily accessible. Of concern though is that patients may not have the ability to understand and contextualize this information into their own lives for lack of health literacy.

The causes of health illiteracy are multifactorial. Authors have linked it to overarching demographics, psychosocial as well as cultural factors. Individualistic characteristics relate to baseline literacy and cognition, sensorial integrity and physical ability, socio-economic standing and social support as well as prior experience with the healthcare system. The prevalence and disposition of extrinsic influences such as political agenda and media coverage are also implicated (Sørensen et al., 2012).

Health literacy is defined by the World Health Organization as 'the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health' (Nutbeam, 2000). In a systematic review, Sørensen et al. (2012) integrated previous definitions of health literacy to come to an inclusive description. They conclude that 'health literacy concerns the knowledge and competencies of persons to meet the complex demands of health in modern society,'

furthering the argument that with suitable progression, individuals are able to take responsibility for their own health, that of their family and community. Coulter and Ellins (2007) argues that health literacy is fundamental to patient engagement.

More encompassing than reading, writing and apprehending medical terms, the conceptual framework of health literacy includes the ability to communicate the needs of the individual with health professionals, as well as understand and act upon verbal and written health information and instructions (Sørensen et al., 2012).

The components of health literacy are described by Nutbeam (2000) to include basic, communicative and critical health literacy. The basic or functional literacy refers to the narrow definition of reading and writing skills required for functional effectivity. Progression to communicative or interactional literacy implies the application of cognitive, literacy and social skills which together allow the individual to extract and derive meaning from multiple forms of communication and apply these into their unique situation. Critical literacy is the actualization of the aforementioned skills allowing for control over life situations. Ascending the levels of literacy is described by Nutbeam (2000) to infer greater autonomy and empowerment upon the individual, assisting them in taking decisive control of their health.

Progression between the different levels is ascribed to variation of communicative content and method and the individual's self-efficacy to act upon these messages. While strategies to improve health literacy are therefore mostly linked to the promotion of general literacy, the critical consciousness of individuals with minimal formal reading and writing skills does not preclude them from achieving high levels of health literacy.

The importance of improving health literacy is underscored by research suggesting that patients with low health literacy are less healthy, have higher rates of hospital admission, are less adherent to treatment regimens and are more likely to experience drug interactions and treatment errors (Coulter & Ellins, 2007). While health literacy is thought to improve the health of disadvantaged populations and ameliorate health inequalities, there is no conclusive

evidence demonstrating that interventions undertaken to this end can improve the health outcomes of patients with low levels of health literacy (Coulter & Ellins, 2007; Pignone, Dewalt, Sheridan, Berkman, & Lohr, 2004). There is evidence to suggest that well-structured written information in addition to verbal professional advice can be used to improve patient knowledge, understanding and allay anxiety related to severity of conditions and prognosis (Coulter & Ellins, 2007).

However, a Cochrane review of 24 randomised control trials of the use of computer-based interactive health communication applications, ostensibly used by patients with a higher baseline health literacy and economic status, had a positive effect on knowledge, clinical outcomes, social support and importantly, self-efficacy (Murray, Burns, S, Lai, & Nazareth, 2009).

2.15 Conclusion

Medical records have evolved from personal reflective memoirs to mass data capturing tools. While this development is primarily aimed at furthering medical research, secondary use of aggregated information for non-clinical purposes is rife and of concern. I have found that the scope and depth of progressive South African laws and statutory regulations adequately protects this information from misuse. Within the jurisdiction of these regulations, the beneficial potential of electronic health records to enhance patient care can be actualized. Socio-technical transition from the paper-based 'regime' to electronic health records can be visualized through the lens of transitions theory and guided by the principles of bricolage and diffusion of innovations model. There is sufficient strategic impetus from the South African government to guide the transition a national electronic health record. While improvement in health records can enhance the quality of care delivered to patients, progressive health literacy can empower patients to become engaged active and responsible participants in their own health.

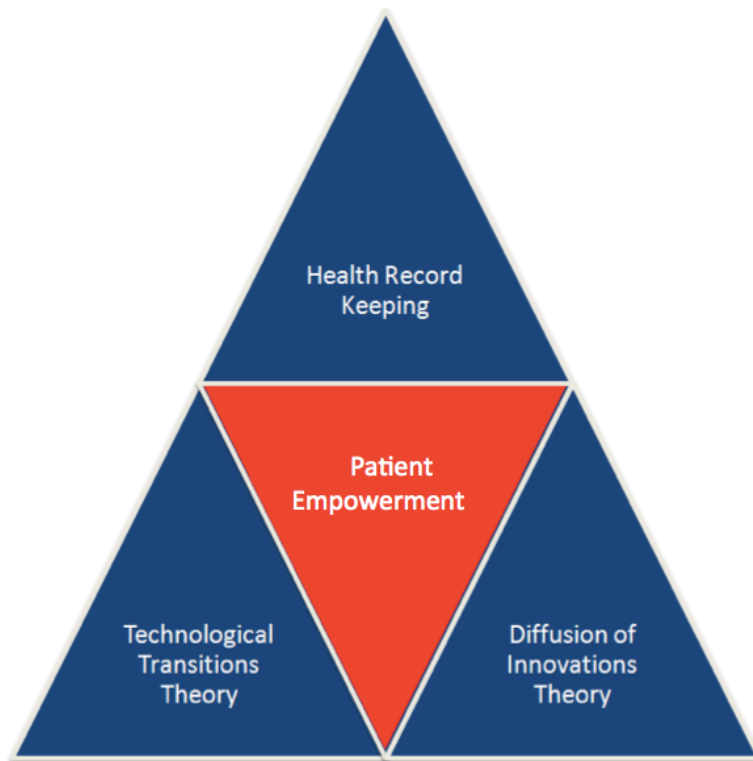


Figure 2.1 Summative diagram of literature review.

3. Research Methodology

3.1 Research Paradigm

Understanding and exploration of the paradigm within which the research question is situated provides a structural framework through which answers may be explicated, and knowledge gained.

Guba and Lincoln (1994) define a paradigm as:

A set of basic beliefs that deals with ultimates or first principles. It represents a worldview that defines, for its holder, the nature of the world, the individual's place in it, and the range of possible relationships to that world and its parts. (p.107)

More specifically, inquiry paradigms are useful for researchers in that they define the scope and limitations of legitimate inquiry. Guba and Lincoln (1994) argue that paradigms fundamentally influence the ontology and epistemology of research methodologies. As a medically trained social science researcher looking to understand the interaction of patients and doctors with medical records, the researcher takes a constructivist outlook or worldview. From this, it can be appreciated that understanding the interconnections between ontology, epistemology and methodology inform the overarching paradigm within which they are subsumed.

Ontology deals with the philosophy of the nature of being, the beliefs and assumptions we have concerning it and questions the form and nature of reality, and consequentially what can be known about it (Guba & Lincoln, 1994). A constructivist ontology, as put forward by Guba, & Lincoln, (1994) apprehends the multiplicity of understandings of reality as, 'intangible mental constructions, socially and experimentally based, local and specific in nature and dependent for their form and content on the individual persons or groups holding the constructions. Constructions are not more or less true, in any absolute sense, but simply more or less informed.'

In contrast, epistemology is a theory of knowledge which rationalizes how we gain knowledge of our surroundings (Blaikie, 2004). Essentially, it's the 'how and why' do we

know what we know. While the researcher's epistemological standpoint has been synthesised over years of experience in the health sciences, and can hence be deemed to be a hybrid of sorts, the foremost are transactional and subjectivist constructivism. As such, the researcher and subjects are linked so that knowledge is created dynamically with progression of the study. Furthermore, von Glasersfeld (1984) observes that we construct our individual realities rather than gain them through perception, such that we inhabit a world of our own making (as cited in Burr, 2004, p.3).

From this paradigmatic outlook, the researcher sees the interview subjects as experts of their individual experiences whose wealth of observations and insights can be used to answer the research question.

3.2 Qualitative research approach and strategy

Brown (2008) describes qualitative research methodology as:

A composite of philosophy, concepts, data-gathering procedures, and statistical methods that provides perhaps the most thoroughly elaborated basis for the systematic examination of human subjectivity. Central to this enterprise are the meanings and understandings that individuals bring to their endeavors (p.3).

Mason (2002) attests to this 'composite' nature, commenting on the heterodoxy of techniques, philosophies, intellectual and disciplinary traditions that it encompasses. Amongst the schools of the interpretivist sociological tradition with which qualitative research is associated are phenomenology, ethnomethodology and symbolic interactionism.

While Mason (2002) suggests that the 'distinction between quantitative and qualitative research is not clear cut,' the former differs from its most established quantitative counterpart in the range of questions it is able to address (Barbour, 2008). Although unable to answer questions related to quantities, causation and quantification of the strength of relationships between variables, Barbour (2008) maintains that it can 'provide an understanding of how official figures are created through social processes.'

In the same way, Schein (1985) points out that rather than generalizing causation, the objective of qualitative research is to gain an understanding of participants and the ways in which they create meaning from their experiences (as cited in Conklin, 2007, p. 276).

Understanding can be gained by contextualizing the explanations, accounts and decision making into participants everyday lives (Barbour, 2008). ‘Context stripping,’ as found in quantitative approaches is claimed by Guba and Lincoln (1994) to be an ‘exclusionary design’ which detracts from the relevance of the study.

As an established form of social science research, support for the qualitative approach is bolstered by Goetz and LeCompte (1984) and Morgan (1986), who go so far as to suggest its superiority over other research methods in its ability to unravel the complexity of processes and phenomena (as cited in Conklin, 2007).

Supporting this argument, and in opposition to qualitative detractors, Bogdan and Biklen (1982) argue:

Qualitative studies are not impressionistic essays made after a quick visit to a setting or after some conversations with a few subjects. The researcher spends considerable time in the empirical world laboriously collecting and reviewing piles of data. The data must bear the weight of any interpretation, so the researcher must constantly confront his or her own opinions and prejudices with the data (as cited in Conkin, 2007, p. 285)

3.3 Qualitative research in the health context

Health sector challenges are complex and multi-layered in that they encompass patients’ liberty and dignity, professionals practice and responsibilities, organizational culture and structure, societal and political values and influences. Caronna (2010) argues that qualitative research methodologies are ‘not only are able to analyse process and change but also allow for diverse and possibly contradictory perspectives.’

The prevalence of healthcare and health systems qualitative research is exemplified by work undertaken from the micro level on practitioner behavior (McDonald et al., 2006; Lewin and Green, 2009), doctor-patient relationships (Lewin and Green, 2009), and provider interactions (Barley, 1986; Shuval et al., 2002); to meso level analysis of organizational structure, culture and strategy on health organizations (Martin et al., 2003; Sheaff et al., 2003; Germov, 2005), effectiveness of organizational change (Buchanan et al., 2007); to macro level studies on health policy, regulatory structure and professional standards by Reay and Hinings, 2005 (as cited in Caronna, 2010, p.76).

Similarly, qualitative research in the field of adoption and dissemination of innovations has been undertaken locally by Lewin and Green (2009), on the implementation of the World Health Organization's tuberculosis protocol, and internationally by Coulter and colleagues (2008), on the reasons underlying the collapse of an integrated medical centre in the United States (as cited in Caronna, 2010, p.75).

In conclusion, qualitative research provides a method of inquiry that is both established in the health sciences, and well suited to the purposes of my research.

3.4 Phenomenological methodology

Phenomenology is movement encapsulating phenomenological thought and philosophical convention. Derived from the works of Edmund Husserl and built upon by Alfred Schutz and Martin Heidegger, the term describes the 'study or description of phenomena' (Cope, 2003).

Sanders (1982) describes phenomenology as:

The science of essential structures of consciousness or experience. It concentrates neither on the subject of experience nor on the object of experience but on the point of contact at which "being and consciousness meet" (Edie, 1962, p. 19). The point of phenomenology is to get straight to the pure and unencumbered vision of what an experience essentially is (p.354).

Phenomena are events or experiences lived by conscious actors. Therefore, as a researcher applying phenomenology, I am concerned with the lived experiences of people (Greene, 1997; Holloway, 1997; Kruger, 1988; Kvale, 1996; Maypole & Davies, 2001; Robinson & Reed, 1998) who have been involved with health records (as cited in Groenewald, 2004, p.5).

As such, a phenomenological analysis uses descriptive examination of lived experiences in order to capture the essence of an event. Furthermore, Sanders (1982) describes the phenomenological process as making ‘explicit the implicit structure and meaning of human experiences.’

Deep contextual understanding of lived experiences is created by the removal of inherent epistemological assumptions (Starks & Trinidad, 2007). This process of phenomenological reduction is termed the ‘epoche’ by Husserl (1977):

The epoche can also be said to be the radical and universal method by which I apprehend myself purely: as Ego with my own pure conscious life, in and by which the entire Objective world exists for me and is precisely as it is for me (as cited in Conklin, 2007, p. 277).

By contrast, existential, unlike transcendental phenomenologists who support Husserl's stance (Jones, 1975; Klein & Westcott, 1994; Osborne, 1994; Polkinghorne, 1983), believe that researchers are unable to detach themselves from their own preconceptions and presuppositions (Groenewald, 2004; Lavery, 2003; McWilliam, 2010). Lavery (2003) cites Heidegger who ‘saw bracketing as impossible, as one cannot stand outside the pre-understandings and historicity’.

In contrast, they comment that the very presence of the researcher influences the lived experience under investigation. McWilliam (2010) proposes that ‘phenomenological understanding is necessarily intersubjective. It arises from the everyday life world where practices and meanings shared between humans become intermingled and merged.’

In order to avoid the impractical impasse of attempting to ‘bracket’ my preconceptions I will use the principles of hermeneutic phenomenology as espoused by Heidegger.

3.5 Hermeneutic Phenomenology

Hermeneutic phenomenology is an interpretive methodology sharing many traits with phenomenology. Lavery (2003) contends that while a clear distinction does not exist between the two, the embedded ontology of the reader and its influence on the resultant interaction with the text and creation of meaning is acknowledged in the former but not the later. As such, hermeneutic phenomenology is described by Allan (1995) as non-foundational as it is inclusive of the meanings created between interpretive interaction of the reader and the text. The foundationalist epoche of phenomenology in contrast seeks textual validity independent of the reader (as cited in Lavery, 2003, p. 27).

While the participant selection, data collection and understanding of the lived experience may be similar in a comparison between phenomenology and hermeneutic phenomenology, issues related to the position of the researcher, explication of data and rigor of the study are dissimilar (Lavery, 2003).

Practically, this methodology allows the researcher to draw upon his experience as a medical doctor working in the public health system and embed this knowledge into the interpretive process.

3.5.1 Rationale

The rationale for using hermeneutic phenomenology as a research methodology in researching a new format for health records lies in its capacity to explore the qualia of the documentation process by users. Healthcare delivery in its most basic form is intimate and individualistic, hence subjectively enacted, experienced and understood. Indeed, McWilliam (2010) observes:

Greater understanding of the complex, multidimensional nature of humanity, human consciousness, subjectivity, intentionality and actions is essential if we are to optimize

the quality of health care, health services delivery and, ultimately, the health of individuals, communities and society at large. Phenomenology offers a way for researchers to address these humanistic aims (p.3).

Qualitative information and insights gained from the phenomenological approach would allow for the co-creation of a locally relevant, practically purposeful health record. Greenhalgh et al. (2008) attests to this in his critique of the failed implementation of the National Health Service's (NHS) summary of care record, which was based on quantitative approaches.

Overall, phenomenology has the potential to promote human development, enhance professional practice, advance the theoretical and practice foundations of disciplines, and inform programmes, services and policies in ways that promote positive change.

3.5.2 Limitations

Limitations of this research methodology relate to its experiential, 'here and now' nature, which according to Cope (2003) provides a 'photographic slice of life. Consequentially, as phenomena are part of dynamic processes, perspectives may change with evolving experience.

A second limitation contended by Gartner and Birley (2002: 394) relates to the 'cluttered and confusing' immersive nature of qualitative research as a whole (as cited in Cope, 2003, p. 170). The mutual interplay between researcher, environment and the subject of interview is uncontrollable and therefore impacts on generation and reporting of findings.

3.6 Data generation- qualitative interviewing

The researcher uses the term 'data generation' rather than 'data collection' as it expresses his epistemological position more accurately: within the field of study, I am actively co-creating

knowledge by dialogue with my study participants, rather than neutrally collecting existing information.

In order to negotiate their way around their world and make sense of it, social actors have to interpret their activities together, and it is these meanings, embedded in language, that constitutes their social reality (Blaikie, 2000).

Qualitative phenomenological interviews were chosen as a means of data generation as it aligns with my ontological stance that peoples' views, experiences and interactions can give meaningful insights into the social reality within which health records are located. Furthermore, verbal dialogue of questioning, listening and reflecting upon participant accounts and articulations is in accordance with my epistemological position on the legitimate generation of data.

3.7 Understanding qualitative interviews

This is an interview technique which provides texturally rich data; descriptions of doctors and patients experiences of interacting with health records in an attempt to discover the subjective and intersubjective meaning of the phenomenon (Groenewald, 2004).

While there are various forms of interviews, Smith and Osborne (2007) argue that the semi-structured approach is most suited to data generation for phenomenological methodologies. In contrast to highly structured standardized interviews where pre-planned questions are presented with premeditated wording, order and response variables by a researcher acting as a neutral instrument, semi-structured interviews allow the researcher to interact with relatively open dialogue such that questions are reactive to and reflective of the subjects' responses. This candid discussion opens up the possibility for the researcher to probe into insights as they arise (Smith & Osborne, 2007).

Kelly (2010) describes this difference as, 'a continuum along which the researcher seeks [greater or lesser] control over the content and structure of the encounter or one in which control over the data is structured more or less tightly.'

3.7.1 How are they performed?

Rather than the control, reliability and speed of a structured interview, the advantages of the semi-structured interview relate to its ability to facilitate empathy, rapport, and flexibility in delving into novel areas considered by the respondent to be important but were not anticipated by the researcher. Smith and Osborne (2007) contend that this approach allows for the ‘unravelling of complexity’ which may be inhibited by a structured interviews need to adhere to a regimented script. As such, the interviewing technique should incorporate both the rigour and subjectivity required to affect the scientific process.

Kelly (2010) cautions that the researcher has to balance the edge of chaos tangential potential of semi-structured interviews with the need to accomplish research objectives. Besides reducing the control the researcher has during the interview process, Smith and Osborne (2007) point out that semi-structured qualitative interviews are also more difficult to analyse.

3.7.2 Instrument of Research -Interviews

A general approach to the principles guiding phenomenological research follows. The interview begins with an attempt by the interviewer to establish rapport with the respondent (Smith and Osborne (2007). The importance of this act, Englander (2012) comments, enhances the subject-subject relationship over the subject-object status quo. While acknowledging the subject-subject relationship as a basis for the interview, Englander (2012) argues that the phenomenological researchers interest lies in the phenomenon as encountered through the respondent. Thus advancing the shift in focus to the subject-phenomenon relationship. As such, during the course of the interview, the researcher has to shift between consciousness of the subject, as well as the phenomenon.

Participants are asked to describe their experience of the phenomenon under investigation, with ensuing dialogue being guided by the respondent. Koch (1996) maintains the importance of open discussion with minimal direct questioning by the researcher so that the interview process stays grounded in the lived experience.

As such, after establishing rapport, and baseline demographic enquiry, the subjects were asked the following question:

Can you describe a time where you have had a positive or negative experience with health records at the clinic?

The subject is therefore encouraged to describe how they experienced the phenomenon, as well as their feelings and actions as a result of this encounter, with the focus on eliciting nuanced descriptions of the multiplicity of the phenomenon, rather than fixed categorization (Kvale, 2007).

The focus is on these nuanced descriptions that depict the qualitative diversity, the many differences and varieties of a phenomenon, rather than on ending up with fixed categorizations. In this way, Kvale (2007) comments that registration and interpretation of the subjects meaning of the phenomenon comes from observation of what is said, how it is said and importantly, what remains unsaid. Furthermore, he encourages the researcher to ‘read between the lines.’

Hence, verbatims do not necessarily capture all of what is ‘really said’ in interviews. ...the importance of paying attention to silence, the absence of speaking, the silence of the unspeakable and the silence of being or life itself, as it is herein that one may find the taken for granted or the self-evident (Laverty, 2003, p.29).

After the opening line of enquiry, Smith and Osborne (2007) states that the researcher is free to probe areas of interest and explore concerns as they arise with a qualified naïveté and openness to the new. While the hermeneutic phenomenological approach does not require the researcher to suspend presuppositions and hypotheses, cognisance is important to elicit the interviewees life world, rather than transference of his own (Kvale 2007). The rest of the interview is given over to exploration of themes, which Kvale (2007) describes as ‘neither strictly structured with standard questions, nor entirely non-directive.’

In conformity to these principles, the researcher used open-ended questions to direct the subject to themes related to the research, allowing them the autonomy to express their own opinions on these themes.

These themes relate to the research sub-questions:

1. Ownership of health records
2. Meaning of health records
3. Confidentiality
4. Health record improvement

3.8 Data storage

All interviews were recorded with the respondents' permission. The rationale behind this is to ensure responses are recorded verbatim for later transcription, without loss of information related to constraints of the human memory or premature analysis. Groenewald (2004) observes that electronic recording allows the researcher to focus on the subject and phenomenon under investigation. Basic precautions such as making sure that the battery was fully charged to prevent equipment failure was taken. While Groenewald recommends that the 'interview setting must be free as possible from background noise and interruptions' the room allocated to me by the clinic's facility manager was unfortunately close to the public announcement speaker resulting in occasional interruptions. Recording took place using the 'voice memos' application on an iPhone. Patient interviews were categorized by the first name of the subject as well as the date, while health workers were assigned a letter. This process was implemented to protect the identity of the interviewee and assure that confidentiality is maintained.

A secondary form of data storage advocated by Loftland and Loftland (1999) is the use of field notes (as cited in Groenewald, 2004). After each interview, I recorded brief notes about the subject, their experience of the phenomenon and points of interest and novelty discussed. However, according to Morgan (1997), 'field notes are already a step towards analysis,' as they are an interpretive derivative of the original interview, they are 'part of the analysis rather than the data collection' (as cited in Groenewald, 2004). Therefore, care was taken not to add judgemental analysis and prematurely categorise information into clusters of meaning.

After the interview, hard copy documents such as the informed consent and field notes were stored in a lever arch file, while recordings were transferred onto a password protected computer for safe keeping. Backup copies of the recordings were stored on a cloud-based program to protect against loss of original information due to hardware failure or theft.

3.9 Sampling

3.9.1 Defining the population

Given (2008) defines sampling as ‘the process of choosing actual data sources from a larger set of possibilities.’ As such, this larger set of possibilities refers to the general population, while the data source refers to the specific sample chosen from that population (Mason, 2002).

Mason (2012) believes that while ‘conventions on sampling in qualitative research are less clear-cut or well established than for statistical sampling and quantitative research,’ and ‘sampling is very often associated solely with a logic derived from general laws of statistics and probability, and used for quantitative surveys,’ rigorous sampling strategies are still important in qualitative studies and demands an alternative to mathematical logic.

Given (2008) defines this logic as the purposeful selection of sources to provide intense analysis for qualitative research, rather large random selection for statistical determination. The concept of population is described by Saumure and Given (2008) to refer to ‘every individual who fits the criteria (broad or narrow) that the researcher has laid out for research participants.’

Saumure and Given (2008) categorises properties related to the overall population as part of purposive sampling. A technical subset of purposeful sampling in defining the population is stratified sampling, which ‘divides the overall sample into specified subsets for comparative purposes’ (Saumure & Given 2008, p.800).

My inclusion criteria or sampling frame for participants are the following patient characteristics:

1. Lower LSM group
2. Clinically stable and attending the chronic disease ‘club’ at a primary level state healthcare facility in Cape Town.
3. Suffering from HIV and/or hypertension and/or diabetes.
4. Between the ages 30-69

The inclusion criteria for the second group of participants are:

1. Health care workers
2. Working in a primary level public sector health clinics

3.9.2 Sampling the population

Mason (2002) comments that while some comparison can be made between sampling categories, they are unlikely to be meaningful. As such, they have been chosen because they provide access in an ‘interpretive sense’ to the phenomenon, namely the experience of health records, rather than selection for their inherent interest.

According to Given (2008), after defining the population, selection of participants to be included into the sample has to be undertaken. Probability and non-probability sampling are the two most basic divisions of this procedure. In the former, Given (2008) writes that members of the defined population have an equal and known chance of inclusion in the sample, and cites random sampling as the most accepted means employed.

This method can provide quantitative statements about the accuracy and statistical significance of the results. On the other hand, non-probability sampling is used when enumerating the size, or giving every member of the original population the same chance of being included in the sample is impractical. As this is the case in my research population, I have used non-probability sampling.

Morgan (2008) attests to this:

Thus, the common use of non-probability samples in qualitative research matches an approach to data collection and analysis strategy that typically relies on the careful interpretation of a small number of very rich data sources (p.5)

While non-probability sampling was used for both groups of participants, different subsets of this technique were used for patients and health care workers. As the former derives from a much larger overall population, convenience sampling was used, while stakeholder sampling was effected to find participants in the latter.

Saumure and Given (2008) write that the convenience sample is made up of participants who are ‘selected based on their ease of availability...who are the most ready, willing, and able to participate...’

As the study took place in a busy, often chaotic clinic without an electronic booking system, variation of patients attending consultations varies greatly. Thus, while convenient, this method has consequences on the external validity of the study (Saumure and Given (2008).

Stakeholder sampling is described by Palys (2008) as a purposive sampling strategy useful for ‘identifying who the major stakeholders are who are involved in designing, giving, receiving, or administering the program or service being evaluated, and who might otherwise be affected by it.’

In this way, I found health care workers at the clinic and academic institutions who have experience with the phenomenon.

3.9.3 Sample Size

Sample sizes are significantly smaller in qualitative studies (Mason, 2002; Groenewald, 2004; Morgan 2008) than in quantitative studies as statistical representation of the entire population and generalizability are not concerns in qualitative research. Instead, Mason (2002) suggests that the focus should be accessing sufficient data to answer the research

question. In fact, Boyd (2001) regards 2-10 participants, while Creswell (1998) suggests ‘long interviews with up to 10 people sufficient to reach saturation (as cited in Groenewald, 2004, p.11).

Morgan (2008) emphasises the view that gaining an understanding of the phenomenon is more important than numerical size of the sample, stating that ‘qualitative researchers are well justified in using criteria such as saturation or redundancy in the data collection, rather than statistical criteria, as a standard for determining sample size.’ Furthermore, Morgan (2008) states that large sample sizes may result in the researcher ‘drowning in more data than it is possible to analyze.’

Based on these principles, I continued to interview participants until thematic saturation and redundancy of novel expression were encountered. Therefore, instead of setting out with a numerical objective, the researcher took a more inclusive approach to data collection. After 17 interviews, recurrence of themes became prevalent, with no new themes found after 19 interviews. At this point, the researcher concluded the data gathering process.

3.10 Location of Research

Research took place at the Vanguard Community Health Centre located on the corner of Candlewood and Citrus Street in Bontheuwel. The clinic provides primary level healthcare to the Bontheuwel and Langa communities in what is known as the ‘Southern-West Substructure of the Metro Region’ serving approximately 105 000 people. While primarily funded by the Western Cape Department of Health, the University of Cape Town’s Faculty of Health Sciences makes use of part of the clinic for the teaching of medical students. This clinic was chosen firstly, because it allowed access to patients from the desired sample population, and secondly as it services the needs of two disparate demographic groups. Langa is home to a predominantly black African population, while Bontheuwel is a majority coloured suburb (Strategic Development Information and GIS Department, 2013).

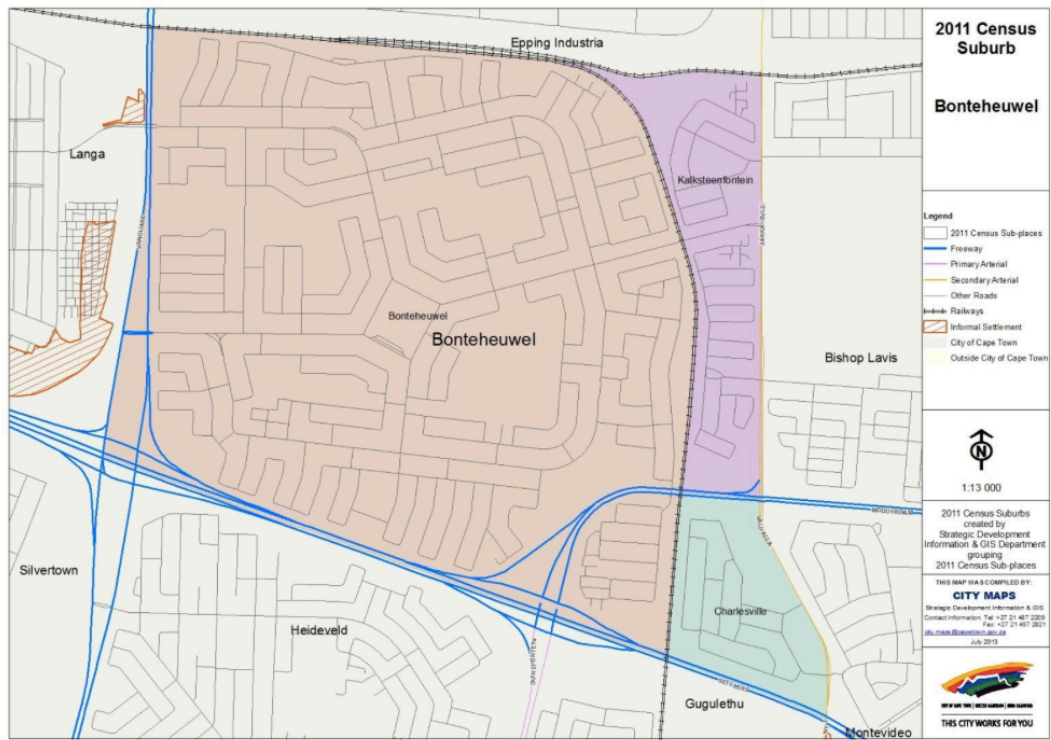


Figure 3.1: Bonteheuwel Suburb

(Strategic Development Information and GIS Department, 2013)

2011 Census Suburb Bonteheuwel	2011
Population	52956
Households	11037
Average household size	4.80

Table 3.1: Bonteheuwel population

(Strategic Development Information and GIS Department, 2013)



Figure 3.2: Langa Suburb

(Strategic Development Information and GIS Department, 2013)

2011 Census Suburb Langa	2011
Population	52401
Households	17400
Average household size	3.01

Table 3.2: Langa population

(Strategic Development Information and GIS Department, 2013)

3.11 Rigor

Rigor is a concept which describes the quality of the research undertaking and the trustworthiness of its findings (Saumure & Given, 2008b). While Davies and Dodd (2002) suggests that the traditional understanding of the term ‘encompasses detachment, objectivity, replication, reliability, validity, exactitude, measurability, containment, standardization, and rule,’ there is an appreciation (Davies & Dodd, 2002; Golafshani, 2003; Moore, 2002; Saumure & Given, 2008c) that an inherent quantitative bias is implicit.

In contrast to Denzin and Lincoln's (1999) anti-positivist stance which views the 'scientific criteriology' of validity, generalizability and reliability as 'irrelevant or anathema' to qualitative research, Moore (2002) proposes that

...the broad ideas which lie behind some of the key principles of scientific criteriology are (not) necessarily problematic in themselves. The difficulties come in if we try to apply the technical procedures which have been derived from the broad ideas and principles directly to qualitative research (p.38).

Supporting this view, Davies and Dodd (2002) believes that whereas rigor does refer to reliability and validity, which needs to upheld, the criteria for evaluation should be appropriate to the research methodology and methods. Albeit the conventional use of reliability refers to 'replicability over time and across contexts,' in the context of qualitative research, Davies and Dodd (2002) argue:

...we aim for a reliability in our data based on consistency and care in the application of research practices, which are reflected in the visibility of research practices, and a reliability in our analysis and conclusions, reflected in an open account that remains mindful of the partiality and limits of our research findings (p.280).

Furthermore, the narrow constraints which define conventional attempts at quantifying rigor should be expanded. While there are multiple contesting approaches to assessing the quality of research (Guba & Lincoln (1999); Landridge (2007); van Manen (1997), I have incorporated two, which are complementary (as cited in Kafle, 2013, p, 195-196).

Saumure and Given (2008c) cite transparency, validity or credibility, reliability or dependability, comparativeness, and reflexivity as quality standards by which qualitative research can be measured. These criteria were used together with the Consolidated Criteria for Reporting Qualitative Research (COREQ) produced by Tong, Sainsbury and Craig (2007), to uphold the rigor of my research.

3.11.1 Transparency

This refers to a clear and comprehensive description of the research process, providing an ‘audit trail’ by which readers can scrutinize the appropriateness of methods in answering the research question, and if need be, replicate the study and verify the results (Saumure & Given, 2008c). Practically, I have implemented the COREQ 32 item checklist to insure transparency.

3.11.2 Validity or Credibility

Validity is a concept within the positivist tradition which has applicability in determining the rigor of qualitative research (Golafshani, 2003; Guba & Lincoln, 1994; Moore, 2002; Saumure & Given, 2008c; Tong et al., 2007). Joppe defines validity as ‘whether the research truly measures that which it was intended to measure or how truthful the research results are. In other words, does the research instrument allow you to hit "the bull’s eye" of your research object?’ (as cited in Golafshani, 2003, p.599)

Whittemore (2001) describes various strategies to enhance the validity of qualitative inquiry:

3.11.2.1 Design considerations

3.11.2.1.1 Sampling decisions:

Stakeholder as well as convenience sampling were used in two separate populations.

3.11.2.1.2 Triangulation:

Creswell and Miler (2000) define triangulation as ‘a validity procedure where researchers search for convergence among multiple and different sources of information to form themes or categories in a study’ (as cited in Golafshani, 2003, p. 604).

The use of triangulation stem from Denzin’s (1970) idea that ‘... the flaws of one method are often the strengths of another, and by combining methods, observers can achieve the best of each, while overcoming their unique deficiencies’ and ‘the combination of multiple methods

– each with their own biases, true – into a single investigation will better enable the sociologist to forge valid propositions that carefully consider relevant rival causal factors’ (as cited in Melia 2010, p. 572) .

In contrast to this view, Bloor (1997) observes that ‘triangulation may be said to involve juxtaposing findings gathered by the best available method with findings generated by an inferior method’ (as cited in Melia 2010, p.570)

While the use of triangulation as a means of enhancing the validity of qualitative research is controversial (Golafshani, 2003; Melia, 2010), the constructivist paradigm, Johnson (1995) argues, appreciates the multiplicity and diversity of realities that are simultaneously held by individuals. As such, the use of ‘within method’ triangulation of approaches to search for and gather data are appropriate. In appreciation of this view, I enrolled the assistance of a peer researcher to conduct a phenomenological group interview (see Sophie and Ayesha) after completing 18 individual interviews. At this point in the research, thematic saturation had already been achieved. However, I used this approach with caution, cognisant of Bloor’s (1983) comment that triangulation can only corroborate findings, and not refute them:

... it is difficult to see the warrant for rejecting findings that are the product of a seemingly appropriate method simply because they are not ‘triangulated’ by additional findings generated by seemingly less appropriate methods

(as cited in Melia, 2010, p. 569).

Another form of triangulation was the inclusion of perspectives from heterogeneous groups, namely patients and health care workers.

3.11.2.1.3 Giving voice:

Semi-structured qualitative interviews empowered participants to express their opinions freely.

3.11.2.1.4 Sharing perquisites of privilege:

The researcher was aware of power relationship and participants were treated as equal subjects

3.11.2.2 Data generation

- Articulating data generation decisions: rationale for semi-structured interviews has been demonstrated
- Persistent observation and engagement: research was conducted over a two-month period in a natural setting to identify the subjective reality of the phenomenon
- Data recording: all interviews were recorded with the iPhone 'Voice Memo's' application to insure accuracy of data capture.
- Transcription: verbatim transcription of interviews took place with safe storage
- Saturation: interviews were concluded after no new themes were discovered after 15 interviews. 5 interviews were performed to corroborate this finding

3.11.2.3 Analytics:

- Articulation: all decisions have been articulated to conform to the principles of hermeneutic phenomenology
- Qualitative computing: NVIVO for Mac was used to code the transcripts into themes from units of meaning. Verification of themes and creation of super-ordinant themes were substantiated by computational analytics built into the software.
- Memoing: ongoing creation of memos took place during the analysis period to note points of interest and contradiction.
- Analysing negative cases: contradictory viewpoints are documented and juxtaposed to illustrate that the researcher is not only looking for cases that support his theory.

3.11.2.4 Presentation

- Researcher perspective: ontology, epistemology and background have been established.
- Supportive evidence: discussions and interpretations are supported by evidence from the literature

3.11.3 Reliability and dependability

Reliability is defined by Joppe (2000) as

The extent to which results are consistent over time and an accurate representation of the total population under study is referred to as reliability and if the results of a study can be reproduced under a similar methodology, then the research instrument is considered to be reliable (as cited in Golafshani, 2003, p.598).

The ‘quantitative bias’ as proclaimed by Davies and Dodd (2002) has however resulted in scepticism by qualitative researchers (Golafshani, 2003; Melia, 2010; Moore, 2002) on the neutral application and standardization of instruments required to check reliability.

Stenbacka (2001) goes so far as to suggest that ‘the concept of reliability is even misleading in qualitative research. If a qualitative study is discussed with reliability as a criterion, the consequence is rather that the study is no good’ (Stenbacka 2001).

As a result, the term ‘dependability’ is advocated (Lincoln & Guba, 1985; Clont, 1992; Seale, 1999) in place of reliability as a measure of rigor in qualitative research (as cited in Golafshani, 2003, p. 601).

Jensen (2008) describes the establishment of dependability as the recognition of an evolving research context, which cannot be understood a priori, and the documentation of reflective changes justified to enable replication of the study. The use of an ‘inquiry trail’ is advanced

(Golafshani, 2003; Jensen, 2008) to demonstrate dependability. In comprehensively documenting the research approach, alterations in the research design and changes in the number of interviews, I have demonstrated the dependability of my research process and findings.

3.11.4 Comparativeness

Saumure and Given (2008c) cite comparability to be a criterion by which rigor can be assessed. Indeed, I have compared cases to one another in relation to themes as well as compared findings with contemporary published research.

3.11.5 Reflexivity

Reflexivity is describes by Dowling (2008) as ‘qualitative researchers’ engagement of continuous examination and explanation of how they have influenced a research project.’ The relational reciprocity of reflexivity between the researcher and participants in co-creating the research has been dealt with in the epistemology and ethics sections.

3.12 Summary

I have illustrated my understanding of quality in qualitative research through the use of Saumure and Given’s (2008c) attributes of transparency, validity or credibility, reliability or dependability, comparativeness, and reflexivity as well as the COREQ criteria produced by Tong, Sainsbury and Craig (2007), and have thus demonstrated the rigor of my research.

3.13 Unit of analysis

The experience of using health records to convey information pertaining to diagnosis and treatment by patients and health workers.

3.14 Data transcription and analysis

Poland (2008) describes transcription to be a process whereby research conversations in the form of interviews and group discussions are converted into textual material, that becomes the primary data for analysis. The ubiquity of the process has resulted in its significance (Poland, 2008; Davidson, 2009) in the interpretive process to be underestimated. Green (1997) describes this interpretive process as:

...what is represented in the transcript (e.g., talk, time, nonverbal actions, speaker/hearer relationships, physical orientation, multiple languages, translations); who is representing whom, in what ways, for what purpose, and with what outcome; and how analysts position themselves and their participants in their representations of form, content, and action (as cited in Davidson, 2009, p.38).

Poland (2008) attests to this, cautioning on the use of the term ‘verbatim’ by researchers in describing the generation of transcripts as ‘they do not capture many elements of interpersonal interaction, nonverbal communication, and interview context that are essential for the interpretation of what is said.’

He believes that if not guarded against, the nuances of the interview may inadvertently be lost. Counterbalancing this argument, proponents of selectivity (Cook, 1990; Duranti, 1997) believe that it is impossible to record all features of conversations, to the point that selectivity should be understood to be a ‘practical and theoretical necessity.’ Furthermore, Ochs (1979) proposes that ‘a more useful transcript is a more selective one’ as non-essential information may cause the transcript to be difficult to read and analyse (as cited in Davidson, 2009, p. 38).

Balancing the principles mentioned above, the first transcription of the audio-recording included everything verbally audible. Kelly (2010) describes these transcriptions to be in accordance with the technique of ‘naturalism’ as repetition, stuttering, interjections, pauses and laughter were included. This was so that reiterations progressed from an original mirroring the interview as close as practicable. Punctuation was however kept to a minimum so that conversation flowed naturally and meanings were not altered.

Recommendations that audio recordings are repeatedly listened to made by Groenewald (2004) were followed. This allowed the researcher to become familiar with the words of the interview participant and develop a comprehensive, multi-dimensional understanding of the phenomenon portrayed. Besides repeatedly listening to the audio recordings for the transcription process, the researcher also adopted the process while analysing the data such that the connection with the original interview was maintained as closely as possible.

Transcriptions play a pivotal role between the gathering and analysis of raw data, affecting the validity of results (Easton, McComish, & Greenberg, 2000). As such minimization of errors is important in maintaining the rigor of the study.

Equipment failures were guarded against, environmental hazards were mitigated as far as possible to prevent extraneous noise from affecting the transcription (Groenewald, 2004).

Common errors in the transcription process include mishearing and misinterpretation of words due to language barriers, and unfamiliarity with jargon and colloquialisms. Easton et al., (2000) puts forward that the researcher should conduct and transcribe interviews to limit these pitfalls stating that ‘as a general rule, just as an analysis can only be as accurate as the person doing it, so also is a transcription only as precise as the person transcribing.’

As a researcher, I conducted the interviews with the participants, gained rapport with them to understand their gestalt and transcribed the interviews with their holistic picture in mind. My medical experience of working with this population on the Cape Flats assisted me in understanding commonly used vernacular and culturally specific turns of phrase to limit misinterpretation.

In accordance with the ethical injunction of protecting participant identity, recordings were anonymised prior to transcription.

3.15 Data analysis

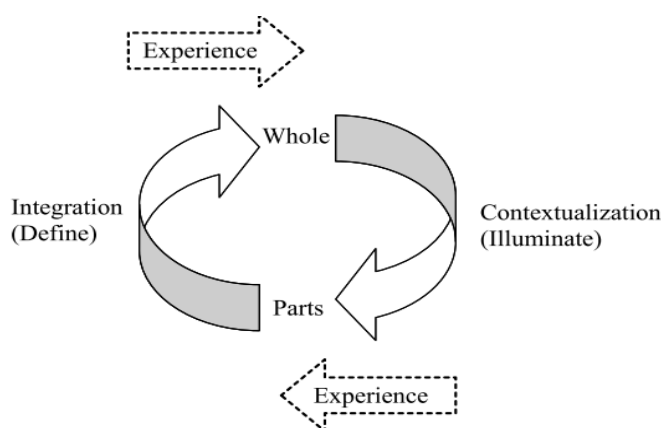
In general terms, analysis is regarded by Coffey and Atkinson (1996) as ‘systematic procedures to identify essential features and relationships’ in data and transforming it through interpretation (as cited in Groenewald, 2004, p. 17).

While more specifically, Van Manen (1997) describes the aim of phenomenological data analysis to ‘transform lived experience into a textual expression of its essence – in such a way that the effect of the text is at once a reflexive reliving and a reflective appropriation of something meaningful’ (as cited in Ajjawi & Higgs, 2007, p. 622).

As such, the researcher used analysis to understand the structure, logic and interrelationships presented by participants in their experience of the phenomenon of health records. Central to this is the understanding of meaning of the data in all its complexity, and in a concise manner portray these disparities and nuances to reflect the core experiences of the subjects. Smith and Osborn (2007) believe that discerning the complexity of meaning rather than its frequency is paramount. The researcher has done this by immersing himself in the text.

3.16 Hermeneutic strategy:

The hermeneutic cycle was incorporated by the researcher as a research analysis strategy. This method is supported (Ajjawi & Higgs, 2007; Blore, 2009; Flick, 2013; Kafle, 2013; Larkin, Watts, & Clifton, 2006; Lavery, 2003) and described to be an iterative process whereby the researcher moves between the part (data) and the whole (understanding of the phenomenon), with each informing the meaning of the other.



(Ajjawi & Higgs, 2007)

Figure 3.3: The hermeneutic cycle

Analysis of the text takes place in a stepwise manner

1. Immersion
2. Understanding
3. Abstraction
4. Synthesis and theme development
5. Illumination and illustration of phenomena
6. Integration and critique (Ajjawi & Higgs, 2007)

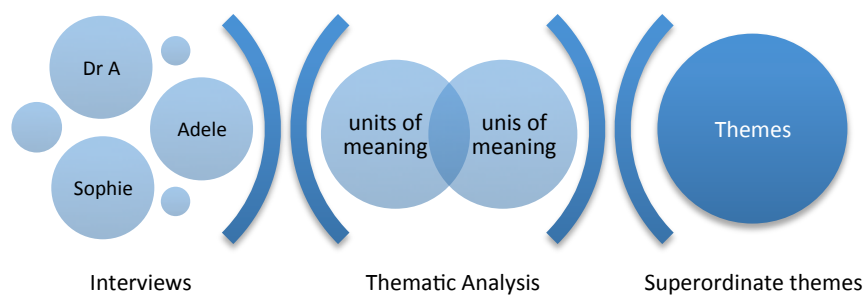


Figure 3.4 Data analysis

3.16.1 Immersion

Transcripts and field notes were read, re-read and audio-recordings were listened to with the transcripts to look for errors, gain a sense of the participant, and contextualize the phenomenon. Formative thoughts were written down in the form of memo's, which were attached to the relevant sections on the physical transcript.

3.16.2 Understanding/ Left Hermeneutic

Delineating units of meaning into the left- hand column of the transcript is described by Groenewald (2004) to be a critical step analysing data. These ‘left hand comments’ are an attempt at:

1. summarizing and paraphrasing
2. creating associations and connections
3. commenting on the use of language
4. preliminary interpretation of the text
5. denoting similarities and differences between participants’ transcripts
6. amplifications and contradictions (Smith & Osborn, 2007)

These units of meaning were applied to the Word document transcript of the interview. This took place while listening to the audio-recording so that the units of meaning were authentically related to the participant. Reference was also made to field notes and preliminary ‘immersive notes.’

3.16.3 Abstraction/ Right hermeneutics

After creating units of meaning, the researcher transferred the document into NVIVO, a qualitative research program. This was to aid in collating, defining and processing the themes which were sub-sequentially created. The researcher created themes by using theoretical and personal knowledge to elicit the essence of the units of meaning within their context. The judgement required in this abstractive process is described by Colaizzi, “particularly in this step is the phenomenological researcher engaged in something which cannot be precisely delineated, for here he is involved in that ineffable thing known as creative insight” (as cited in Groenewald, 2004, p.19).

As part of the hermeneutic cycle, contextualization and integration between the whole and the part meant that in the creation of themes, the researcher always referred back to the original words and units of meaning. This was to insure thematic grounding in the participants experiences (Ajjawi & Higgs, 2007).

Smith and Osborne (2007) describes the skill required in generating themes as ‘finding expressions which are high level enough to allow theoretical connections within and across cases but which are still grounded in the particularity of the specific thing said.’

These themes were assigned as ‘nodes’ in NVIVO, which automatically categorized textual material across participants under the same node. These nodes were later used for comparison of themes between participants. However, Smith and Osborne (2007) caution that care should be taken to ‘discern repeating patterns but also acknowledge new issues emerging as one works through the transcripts,’ with the aim of respecting ‘convergences and divergences’ in the data. Mason (2002) concurs, stating that while the themes should be consistent, ‘they are unlikely to be uniform.’ In accordance with these injunctions, I created loose thematic descriptions against which the phenomenological expressions were compared and contrasted for congruence.

3.16.4 Synthesis and theme development

After themes were classified into nodes, analytical and theoretical ordering by the researcher, resulted in the creation of thematic clusters of superordinate and sub-themes. Smith and Osborn (2007) describe this a ‘magnet with some of the themes pulling others in and helping to make sense of them.’

Again, the process of sense-making revolves around the hermeneutic cycle of ‘part to whole’. While making sense of what the participant is saying, the researcher has to simultaneously check his own sense-making against what the participant says. Using NVIVO, I created directories of participant phrases and coded these to individual or multiple themes. Therefore, the researcher could look to corroborate the original evidence from the transcript with themes within clusters to assure theoretical consonance. The process of creating superordinate themes is challenging as prioritization of thematic importance is not based on prevalence alone, but the significance ascribed by the participants in their explanation of the phenomenon (Smith & Osborn, 2007).

Van Manen describes this as; “In determining the universal or essential quality of a theme our concern is to discover aspects or qualities that make a phenomenon what it is and without which the phenomenon could not be what it is” (as cited in Ajjawi & Higgs, 2007, p.625).

3.17 Conclusion

The researcher made use of the hermeneutic cycle to identify essential relationships within the phenomenological expressions of participants to transform the data into congruent and understandable themes.

4. Research findings, analysis and discussion

How does the experience of chronic disease patients with their health information inform the development of future health records in low income population groups?

A brief description of the research participants is given below to contextualise their experience of medical records, within the framework of the research question and proposition.

The table below presents the participants' demographic information and duration of interviews.

Participant	Designation	Gender	Age	Interview duration
Adele	Patient	Female	53	14 min 21 sec
Ayesha	Patient	Female	35	40 min 09 sec
Charles	Patient	Male	65	20 min 22 sec
Clifford	Patient	Male	60	20 min 22 sec
Dr A	Doctor	Female	30	28 min
Dr B	Doctor	Female	27	23 min 34 sec
DR E	Doctor	Female	25	18 min 36 sec
Dr G	Doctor	Female	32	16 min 58 sec
Dr L	Doctor	Female	26	15 min 22 sec
Dr M	Doctor	Female	26	16 min 34 sec
Dr R	Doctor	Female	33	11 min 10 sec
Dr T	Doctor	Female	30	18 min 36 sec
Mhlabane	Patient	Female	51	11 min 34 sec
Millicent	Patient	Female	48	8 min 28 sec
Nosipho	Patient	Female	31	9 min 53 sec
Ntomnovuyo	Patient	Female	57	9 min 54 sec
Nurse Z	Nurse	Female	54	15 min 10 sec
Prof H	Doctor	Male	61	26 min 10 sec
Sophie	Patient	Female	55	40 min 09 sec
Vanessa	Patient	Female	54	39 min 47 sec

Table 4.1 Summary of interview participants and duration.

Semi-structured phenomenological interviews were used to evoke participant experiences, with the use of the interview question:

Can you describe a time where you have had a positive or negative experience with health records at the clinic?

While I introduced the following themes into the interviews, in keeping with the constructivist epistemology, I allowed the data to speak for itself.

1. Meaning of health records
2. Ownership of health records
3. Confidentiality
4. Health record improvement

4.1 Interview Participants

4.1.1 Adele

Adele is a 53-year-old employed female from Bontheuwel. She suffers from diabetes and hypertension and follow up at the Vanguard chronic care club, with occasional visits to Goodwood clinic as it is closer to her place of work. She feels that the care at Goodwood CHC is superior to that provided at Vanguard CHC. She has also been investigated at Tygerberg Hospital for an unrelated gynaecological condition. She claims adherence to her medication but fears having a heart attack. She describes an experience at the community health centre where she presented at 6 AM and waited till 12 PM to be seen. At this time, she was told that her folder was missing. This, combined with her inability to remember the names of her medication resulted in her only accessing emergency treatment for hypertension and hyperglycaemia. Pointing out that access to care hinges on access to clinical information, she was embarrassed at not knowing the names of her medication.

4.1.2 Doctor B

This is a 27-year-old medical doctor. She is performing her community service at Vanguard CHC. As a junior doctor, she works in the chronic care and outpatient clinics. She is frustrated by pervasive system inefficiencies and cites patient ambivalence towards their own health as concerning. While attempting to empower patients, her disposition is towards paternalistic healthcare. She reports sending patients home to collect their medication packets if they cannot communicate their medical history with her. She describes this process as time consuming as she has to reinitiate the process of history taking, examination and re-investigation of the patient. She also comments on the unstructured nature of medical records which increases the time taken to see a patient by an additional 5-10 minutes. She employs a form of bricolage to deal with these problems, providing patients with a copy of their quadruplicate chronic medication script to bring along with them at future consults pre-empting a loss of records.

4.1.3 Sophie

Sophi is a soft spoken 55-year-old lady from Langa who attends the chronic club for management of her epilepsy and hypertension. She has difficulty accessing the clinic as she lacks the money needed for transport. She expresses the importance of knowing about her clinical conditions and her family is aware of acute seizure management. While expressing ideas of self-efficacy, she places considerable trust in the role of the doctor as a healer. While experiencing the medical consult as satisfying and therapeutic, she describes the storage of folders as chaotic, with retrieval being difficult and a cause of frustration. She often looks through her folder for information on her conditions and frequently asks for clarification when unsure of terms. She does not however know the names of her medication.

4.1.4 Ayesha

Ayesha is a young hypertensive patient following up at the chronic club. She has considerable awareness of her medical condition. While critical of the doctor's ability to adequately diagnose and treat her acute conditions, she has insightful comments regarding the improvement of medical records at the facility. She describes the experience of seeing a doctor at the clinic as being overly complicated as she has to take her folder from one room to another before accessing care. She describes the process as frustrating and would prefer to see a private practitioner to save time. Pointing out that the notes are often illegible, she often has to ask for clarification from her doctor. She wants her records to be more organized

with notes arranged chronologically and indexed for ease of understanding. She feels this to be the hospitals responsibility.

4.1.5 Charles

Charles is a well-spoken 65-year-old chronic disease sufferer who was down-referred from Groote Schuur Hospital to Vanguard CHC 7 months ago after being diagnosed with an endocrine disorder. He has good insight into his condition, which he has researched extensively. Due to the extensive counselling and health education he received while admitted to Groote Schuur, he is able to titrate his medication with a fair sense of autonomy.

He believes that health records provide a useful means of communications between the multiple doctors who treat him at the clinic. He is comfortable describing his medical conditions, medication and dosages in their absence. He is keen on using a personal health record and feels that it will prevent medical miscommunication and resultant iatrogenic drug interactions and complications. Both of which he previously experienced. Furthermore, he comments that if he is incapacitated, a personal health record will alert practitioners to his penicillin allergy, which he fears may go undetected.

4.1.6 Dr R

Dr R is an experienced medical officer who has worked at the Vanguard facility for 5 years. As the senior in charge, she has multiple clinical and administrative responsibilities, including supervision of junior staff. She describes the folder system to be inefficient and inadequate for the large population base which the clinic serves, who she feels are passive recipients of healthcare. She states that 10% of patients' folders go missing on a daily basis. While her experience of the clinics record keeping system is generally negative, she comments that the use of a personal health book by patients from the Eastern Cape is informative and assists in promoting continuity of care.

4.1.7 Dr G

Dr G is a senior medical officer at Vanguard CHC. Oversight of the chronic club and acute admissions ward is her responsibility. The frequency of folders going missing, she emphasises to be the cause of significant patient inconvenience, increased medical and administrative workload and overall inefficiency. She views these as impediments to patient health. She describes the creation of a new folder (in the absence of the original) as a source

of friction between clinicians and patients, with each party assuming that the other should be more knowledgeable and take more responsibility. She also describes the dependence on paper format, written records as the dominant means of communication in the public health system.

4.1.8 Vanessa

Vanessa is a 54-year-old female who was medically boarded after a workplace related injury which required an MRI investigation at Groote Schuur Hospital. She suffers from diabetes and hypertension, which are both moderately controlled. She has followed up at the Vanguard CHC after moving from Gauteng in early 2015. Long waiting times to access her folder and poor communication from the medical staff are her primary concerns. She describes the process of obtaining her folder as a source of frustration and suffering as she has to wait for 6 hours on a hard bench, worsening her back pain. She feels that if her records were stored on a flash-stick, it would circumvent this process and help communicate her information when she is in Johannesburg. She describes being uninformed about what doctors write in her medical record and claims that clinical information is being withheld from her. Furthermore, she comments that doctors spend more time ‘writing and writing’ without taking note of her, underestimating her capacity to understand.

4.1.9 Doctor T

Doctor T is a 30-year-old practitioner who works in the chronic club at Vanguard CHC. She advocates patient empowerment through education and enhancing the quality of her consultations. A formalised version of the Eastern Cape health book, she feels would adequately provide continuity of care in a manner that’s socially acceptable to her patient demographic. Doctor T describes her experience of medical records as ‘frustrating’ and ‘unsatisfying’ to her and disempowering to her patients. She expresses the concern that the time wasted retrieving previously generated clinical information results in poor quality consultations with her patients. She observes that loss of information results from folders being misplaced; duplicated with multiple incomplete copies alternatively accessed; or simply poorly structured. Whereas the loss of a folder, in Doctor T’s experience, can lengthen the consultation by 15-20 minutes especially with the elderly, inaccurate or incorrect documentation from previous health workers can also negatively affect the continuity of patient care. She cites the incorrect presence or absence of the term ‘for palliation’ as a grave example of miscommunication.

4.1.10 Clifford

Clifford is an outspoken 60-year-old male with coronary artery disease. He had a 3 vessel coronary artery bypass graft at 47 at a private hospital. After being medically boarded, he was transferred to the public health sector, where he has followed up for the past 13 years. He has a firm belief in patient rights and criticises the relational imbalance in the health transaction. He claims that health care workers ‘hardly write any notes.’ Moreover, he contends that there is an unsaid institutional rule that patients should not look through the medical records. He goes so far as to suggest this is to cover up medical negligence.

When discussing the possibility of patient held records, he pointed out a previous experience where his suggestion that the attending physician write down his medical history for his keeping was dismissed. Again, he asserts that this is due to doctors protecting their own interests. Clifford puts forward that his indifference to potential folder loss originates from his understanding and ability to communicate his medical history. Attributes he believes many patients do not possess.

4.1.11 Ntomnovuyo

Ntomnovuyo is a 57-year-old female patient who previously attended Langa CHC. After defaulting on her chronic medication for 4 months, she has presented to Vanguard CHC. She has taken an independent decision to move between clinics as she is anxious to receive care and fearful of being ‘shouted at by the staff’ at Langa CHC, having defaulted on her medication. Despite her original folder containing her medical information being located at Langa CHC, she does not believe that moving between facilities will have a negative impact on her health. Moreover, while having being on treatment for 7 years, she does not know the names of her medication. However, she contends that she is able to identify them based on the appearance of the packaging. She expresses the opinion that a personal health record will serve as a reminder for her to take her medication.

4.1.12 Doctor L

Dr L is a young medical intern who is new to Vanguard CHC. She finds it difficult communicating with patients due to the language barrier. She also comments that patients rely too heavily on doctors for the management of their health. Missing information or loss of patients’ folders creates frustration for her as she is clinically inexperienced. Thus, she

maintains that for her to suitably manage a patient, she requires previous diagnoses and names of medication, which patients often cannot provide. In the absence of this information, she reports having to perform lengthy clinical history taking, re-examination and re-investigation of patients. Moreover, when the medical record is present, its unstructured or ‘jumbled’ state makes it difficult for her to know what was previously done for the patient. She comments that time and effort could rather be used to educate patients on their disease complexes.

4.1.13 Millicent

Millicent is a 48-year-old female from the Eastern Cape. Although she has been treated for chronic hypertension for the past 11 years, her understanding of the disease is limited to its name and that ‘it’s too dangerous.’

4.1.14 Nosipho

Nosipho is a relatively well educated lady who was forced to leave school after falling pregnant. She is unemployed, and has not worked. At 31, she is a young hypertensive secondary to post-partum pre-eclampsia. Her understanding and insight into her condition are limited. She lacks the rationale behind taking medication, expressing neither autonomy nor informed decision making. Doctors have prescribed medication, to which she complies without question. When transferring from a private general practitioner to the Vanguard CHC, she did not have a referral letter documenting her previous medical history. Consequentially repeat investigations had to be performed. Thus far, she has not opened her medical record to view its contents, nor has she either asked for an explanation or researched her condition independently. However, she believes that personal health records would serve as a reminder to her and be a source of information for further consults.

4.1.15 Dr M

Dr M is a young medical intern who is rotating through Vanguard CHC as part of her family medicine rotation. She describes her frustration with the medical record keeping system when folders go missing, with resultant time and resource wastage. She believes that in the time taken to see one patient whose folder has gone missing, six patients can otherwise be seen. Having to ‘start from scratch’ she points out, firstly results in progression of disease rather than advancement in management, and secondly, contributes to the overburdening of the facility with patients being called back more frequently and unnecessarily. Doctor M

highlights the power dynamic which exists between doctors and patients and its role in patient disempowerment, pointing out that when asked what is wrong with them, patients direct her to open their folders. While admitting that patient education is partly the doctor's responsibility, she affirms the need for patients to take some responsibility for their own health.

4.1.16 Prof H

Prof H is an academic from a local university. He has extensive experience in primary and district level healthcare in the public sector and previously served as a private general practitioner. He sees much benefit can be derived from the implementation of a patient held record but cautions that a demonstrable benefit to both patients and doctors is needed for adoption to take place. Based on his previous experience of public health projects, he suggests that an incentivizing structure may be required for successful rollout, implementation and adoption of a new format health record, with the recommendation that this can be performed within the ambit of statutory continuous professional development (CPD) requirements. However, he cautions that care needs to be taken in the choice of partnering organizations in order to maintain ethical standing and prevent conflict of interest.

4.1.17 Nurse Z

Nurse Z is a 54-year-old professional sister working as a locum at Vanguard CHC after 26 years of service at Crossroads clinic. Missing information and the inability of patients to communicate their health information were frequently encountered in her experience. In Nurse Z's opinion, the loss of a folder is 'the most challenging thing that you get' and causes her to 'scratch her head.' She comments that it results in the abrogation of all previously accumulated continuity of care management strategies and forces her to restart medication based only on the clinical information available on the day of consultation. She reports the current use of two analogous patient-held records which assists in continuity of care when the original folder goes missing; the 'smart card' which had been in use at her previous facility and the Eastern Cape health 'bookie' – a rudimentary bricolage record comprising half an A5 exercise book.

4.1.18 Dr A

Dr A is a 30-year-old medical officer at Vanguard CHC. She describes the loss of a folder as a break in the continuity of care thread needed to sustain quality patient management. She described the frustration associated with missing information and points out measures used by her to assist in continuity of care: providing patients with a copy of the Chronic Diseases Unit (CDU) pharmacy prescription, and sending them home to fetch their medication packaging if other measures fail. She speculates that patients are medically illiterate citing their description of medication by physical attributes such as colour, size and shape rather than name. Whilst the innovative use of bricolage is used in assisting patients recall their medication, in the form of a medication package board she was unaware of an existing pharmacy management resource from which, the same information can be gleaned.

4.1.19 Dr E

This is a young medical intern who is new to Vanguard CHC. She finds difficulty in communicating with patients due to the language barrier. Missing information or the loss of patients' folders creates frustration for her as she is clinically inexperienced and requires more background clinical information for their management. She describes a scenario in which a life threatening arrhythmia (atrial fibrillation) was found on a patient's electrocardiogram (ECG). Prior to transferring the patient for emergency care, the old folder was found and comparative ECG demonstrated the finding to be old and hence non-acute. Equally important are her descriptions of the inadequacy of the folders contents; illegible and incomplete notes affect the quality of patient management and may lead to medical errors. In the same way, she believes that these systems errors lead to a breakdown in confidence and trust between patients and doctors. Despite this, Doctor E points out the inherently high expectations patients have of doctors and contrasts these with their own lack of ownership of their health.

4.1.20 Mhlabane

Mhlabane is a 51-year-old hypertensive patient who follows up at Vanguard's chronic care club. While having trained as a teacher, she was unable to find suitable vocational employment and has worked at a supermarket for the past 20 years. Fear of death motivates her to take her medication, although she cannot name her tablets. Her self-expression is typical of a passive recipient of care within the health transaction and bemoans the long

waiting times to see the doctor. She sees some benefit of a personal health record ‘to the doctors and nurses’ but significantly, not for herself.

Name	Node	Reference
Adele	16	40
Ayesha and Sophie	33	127
Charles	20	48
Clifford	33	78
Dr T	45	139
Dr A	41	90
Dr B	28	89
Dr E	29	68
Dr G	37	94
Dr L	31	67
Dr M	34	78
Dr R	28	60
Mhlabane	11	14
Millicent	1	1
Nosipho	12	14
Ntomnovuyo	18	25
Nurse Z	16	29
Prof H	17	33
Vanessa	61	217

Table 4.2 Thematic analysis by participant

Thematic analysis of the interview data collected at Vanguard Community Health Centre resulted in the creation of 123 themes established by literal, interpretive and reflexive reading of the data (Mason, 2002).

I categorized these into 6 superordinate themes which encompassed the meaning of the underlying subordinate themes. While NVIVO was used to organise the data, analysis was done by the researcher without the use of ‘auto-coding’ algorithms.

These are:

1. Health records as a critical component of clinic infrastructure and workflow organization.
2. Records as a source of information and means of communication.
3. The interplay between health records and the quality of patient care

4. Emotions associated with the experience of health records.
5. The role of health records in patient education, empowerment and the ownership of disease.
6. Health record innovation.

Combined, these superordinate clusters accounted for 117 of the 123 themes. In analysing the outliers not included in the 6 clusters, I did not feel that they meaningfully complemented, contradicted or detracted from the results to affect my ability to answer the research question. These were therefore removed from further analysis.

Themes	Number of participants contributing	Nodes
Information and Communication	18	152
Health record innovation	17	113
Education and empowerment	15	86
Patient care	18	83
Experiences	14	65
Health systems	13	64
Health ownership	14	24

Table 4.3 Theme contributions and citations from transcribed data

4.2 Thematic Analysis

4.2.1 Theme 1: Health records as a critical component of clinic infrastructure and workflow organization.

This superordinate theme was derived from the amalgamation of 12 subthemes. Together, it represents the expressions of 13 research participants and was referred to 64 times in the data.

The magnitude of healthcare services required to meet the needs of the combined populations of Langa and Bontheuwel is observed by participants. While 2011 census figures cite the populations of these suburbs to be in the region of 50 000 respectively, participants believe that repeat visits, which can be up to 3-4 per patient per annum, increased the workload on

the clinic. As doctors cannot remember individual patient details of such a large population, documentation and storage of this information needs to take place.

Health records at the Vanguard CHC are paper-based. They take the form of A4-sized yellow cardboard folders with patient identifying information on the front. This comprises the patients name and surname, hospital folder number and address. Administrative information related to patient classification as fee-paying, medical aid and non-fee paying is also included. Contained within the folder are a loosely-ordered collection of double-sided lined pages of clinical notes, referral letters, biochemical results and prescription charts. The back of the folder has a tabular format area for the recording of radiological investigations. From this, it is apparent that the folder has a central role in co-ordinating and transforming the patients experience of numerous clinical systems and workflow processes required for their care.

4.2.1.2 Workflow Organization

As seen schematically, participants described the experience of attending clinic to be a lengthy process involving multiple steps with the folder playing a key role in documenting the successive interactions.

The patient journey begins at the clinics reception area where they present a form of identification and appointment card so that their folder can be retrieved from archives. Once the folder has been found, patients proceed to the preparation room where they are seen by nurses who triage them and perform basic vital signs such as heart rate, blood pressure and blood glucose testing for diabetics. After waiting to be attended, patients are seen by the doctor who interrogates the folder, summarizes their clinical status, takes a clinical history and examination before proceeding with a future management plan, which may include the retrieval of results or request for further investigations. In most cases, patients proceed to the pharmacy queue to collect medication that was prescribed, before returning their folder to reception for storage.



Figure 4.1 Clinic cycle of interactions

4.2.1.3 Organization of Folders

Overall, participants felt that storage and retrieval of records were a source of consternation and led to significant inefficiency in all downstream processes. This is described by

Doctor R:

Reception has the folders. If you go there and see what that place looks like its havoc. You have your systems where the folders are. But you have a lot of folders which are not filed as yet. There are heaps of folders. So now somebody might come today and you ask them to come in two days' time, that folder might not be filed. Then they issue a new folder. So I've even tried going in there looking for a folder myself but it's not that easy.

Doctor R

The loss of folders will be covered in more detail in theme 2.

Participants' frustration with the organization of medical archives was brought up repeatedly. They felt that there were insufficient staff working in the department for it to function optimally and that those working in archives did not understand the importance of retrieving patients' original folders. In many cases, they felt that creating a duplicate was an easier option for these workers as it placated those who arrived early and waited, passing on the problem to staff working downstream.

Because even though you come here and you sit here five o'clock or six o'clock in the morning... they have to look for your folder and you wait and then other people come 8-o'clock or 9 o'clock and they getting their folder with you. And they don't tell you straight away that they can't find your folder...we looking for your folder. They make you go there to the counter and wait. It's terrible because we sitting here from five o'clock. I mean there are old people. Some people I know are sitting here and me with my back problem, I can't sit for very long, I can't stand for very long. And I can't walk for very long because of this back problem. And for you to come sit here for five or six hours. It's a no no.

Vanessa

What is interesting is that while inefficiencies in the system of retrieval of records were brought up by both healthcare workers and patients, their natures varied considerably. For doctors, concerns related to a perceived increased workload and decreased satisfaction with the quality of the consultation, while patients primarily complained about the time spent accessing care.

When discussing the reliance on paper-based records with participants, in view of the challenges associated with them, their institutional dominance became apparent. Doctors were not able to conceive working without them, as they had become ingrained in their work routines. Discussions on alternative means of record keeping were often seen by participants

to be a backup or subordinate to the established folder-based record. Reasons given by participants reflected the internalization of a resource-constrained environment:

I think if we were making notes on the computer or dictating then that would be fine, but if we had to do it in addition with writing it would take time. Because it would be easier for both the doctor and the patient. But with resources, I'm not sure that it's likely that we will have a computer in every room.

Doctor L

This resource constrained environment is described by participants to be an aggregation of poor funding for technological rollout, insufficient infrastructure and overburdening of the system. Combined, this results in time, system and resource inefficiency.

Doctor A points out that the medical officers at the facility have a daily patient quota which they are required to meet. 40 patient consultations translate to 8 minutes spent per patient in the doctor's 8-hour day. While patients have to wait up to 6 months for successive clinical consultations, and spend 6 hours in the clinical cycle of interactions, their time spent with the doctors is brief. Participants observe that more time is spent accessing the folder than any other step in the cycle of interactions.

Doctor E observes that an ideal solution to this would be the digitization of records. As accessing records is a crucial step in progression through the clinic, improvement in its efficiency is key to enhancing the patient experience. She does however caution on the potential adverse effects that these systems may have on workflow and its qualitative consequence- time.

In an ideal world, it would be lovely. Put it on the system and access it. But you would have to have the means at the facility to access it. Otherwise it may just make you take longer.

Doctor E

Thus far, I have described the importance of accessing health records. The process of documenting clinical information in the health record for continuity of care is an integral part of the clinic staff's workflow processes. Participants observed that these records needed to be easily accessible, transferrable and convenient for inputs or data feeds.

Prof H underscores the importance of health records as a workflow process when he says

If it were part of what they must complete at the end of each consultation, then it wouldn't be a barrier, because they have to see a certain number of patients each day, and most of them are overworked and they going to try and save time on admin, so it has to be part of their record keeping. And not an extra.

The versatility of written records as experienced by participants relates to the files ability to connect disparate parts of the organization in a simple and relatively effortless manner. While participants often criticized the difficulty in accessing records and subsequent frustration caused, they were positive when describing the ease of coordinating patients' care within the facility. Ordering biochemical investigations, referral to allied health disciplines such as physiotherapy or dental services, and movement between parts of the clinic such as chronic club to the accident and emergency department in the case of emergencies can be performed with a short note in the folder or a ticking a block on the relevant form. Participants reported this decreased the administrative component of patient care making it easier to navigate the complex web of interactions that defines a visit to the clinic.

4.2.1.4 Conclusion:

Health records play a key role in co-ordinating and documenting the patients access to and interaction with healthcare services at the clinic. Paper-based records are relied upon for their versatility of use in managing workflows at relatively low cost. Inefficient retrieval of records from archives has created long waiting times for patients to access care.

4.2.2 Theme 2: Records as a source of information and means of communication.

This superordinate theme is an amalgamation of 18 subthemes, comprising the expressions of 18 participants and was generated from 152 citings within the original data set.

While the patient's folder acts as a flexible conduit mediating the patient's navigation through the clinic, the health records primary purpose is for the storage of information pertinent to the patient's clinical conditions. This information is indispensable to the clinician's understanding of patient's background health status within which their current complaint can be contextualized.

I would want to know their medical history. I want to know in terms of presenting complaints and what has been done for that visit and medication that's now boarded.

Has anything changed and whether the plan is to continue? To re-evaluate in a month?

And to follow up? When?

Doctor T

Depending on the complexity, severity and multiplicity of comorbid conditions, participants express that the medical records can be more or less challenging to interpret. Doctor R described the SOAP (Subjective, Objective, Assessment, Plan) model for writing clinical notes. She reports that clinicians are expected to write the date and time followed by a point form list of diagnoses, the patients 'subjective' description of why they have presented, the doctors 'objective' clinical evaluation and findings of vital parameters, followed by an assessment and future plan. Participants corroborate this, expressing that following this system of note keeping facilitates and promotes continuity of care within the clinic whilst the patient is seen by a variety of clinicians.

Contrasting views on the reality of the quality and contents of health records were expressed by participants. Doctor L experienced the records negatively, stating that:

It's pretty frustrating, sometimes there would be random pieces of paper, not an actual file. All jumbled. It's difficult to follow what's happened. Most people don't sign or date their notes correctly. If they do at all. It's just quite a frustrating process.

Other participants' experiences of the quality of their colleagues' notes were more favourable, stating that in most cases, notes, when they were present, followed the prescribed format, enabling them to discern the patients baseline clinical status. A more senior participant, Doctor A, who had worked at the clinic for five years at the time of the interview believed that the ability to scan through patient records of varied complexity and documentary duration was a skill that she had acquired.

If you work in a clinic with such a high patient load, you begin to be able to scan through the folder, pick up the important points and speak to the patient, find out where they are at. It really depends on the patient. If you have a very thick folder with a lot of current complaints, it's going to take a lot longer. But generally, we all have the same format, point form diagnoses, why you are here today, vitals. I think I've become trained in thinking a certain way.

Doctor A

This skill, she declared allowed her to understand a patient's history within a few minutes of presentation, so as to proceed with a rigorous and evidence-based management plan. Prof H attested to the importance of protocol based management of chronic care patients for effective care and efficient running of the clinic. Alternatively, a junior doctor had more difficulty gaining an understanding of patient's background from the folder.

It depends if it's particularly badly organized- so the notes aren't kept together and the prescription charts aren't kept in terms of date. Basically its difficult so you end up with the last one from 2014 but there's none from 2015. So that makes it a bit frustrating. But it takes around 5-10 minutes depending on how thick the folder is to get a good idea

Doctor B

Thus, health records can be seen to be an important source of information during the consult for the management of patients, as well as the basis upon which continuity of care is

provided. The absence of information was brought up by the majority of participants, both health care workers and patients, as a significant concern.

Missing information was ascribed by participants to result from multiple causes. These include illegible handwriting, insufficient or scanty documentation of clinical information, missing pages within the folder, to the entire folder going missing. As these factors were brought up numerous times by the majority of participants, and relate directly to the research question, as challenges and limitations associated with paper-based folder contained records, they will be addressed individually and in some depth.

Concerns over doctors' handwriting were brought up by both groups of participants. Doctors described illegibility of previous data inputs into the health record adversely affected their ability to manage a patient. Especially, where the current presentation was a follow up from the previous consultation and related to a change in management, medication, or a directive to further investigations. Patient participants' experiences of poor handwriting related to their inability to gain a further understanding of their conditions from reading the record either before or after seeing the doctor. Participant Ayesha, a young chronic hypertensive, reported that while she sought information from the folder to enhance her understanding of her condition, illegible notes meant that there was very little that she could gain.

Participants described incomplete information in the record to be source of frustration. This will be elaborated upon in theme 4. This complaint was however prevalent amongst the more junior health care workers. While the senior doctors described their ability to fill in the gaps, which they gained from years of experience managing similar conditions, junior doctors were more reliant on past notes to continue management that had been established.

We find it very frustrating, most of the time when we have old notes I've found that it's helped me a lot. Most of my colleagues have great handwriting and make thorough notes. Sometimes you can't read what's written as they make such succinct notes that you can't actually...they write that the examination may have been normal but something subtle may have been missed.

Doctor E

As continuity of care is dependent on maintaining the clinical progress gained from previous consultations, having those notes accessible is of paramount importance. In the current system, where health records are contained as loose sheets of paper within a cardboard folder, lack of coherence and systematic order means that making sense of a thick folder is particularly difficult. Participants, such as Doctor B describe this sense of frustration. When pages go missing, the sense making process becomes more difficult. When entire folders go missing, which occurs frequently at Vanguard CHC, sense making is greatly impaired. The topic of missing folders was brought up by 13 participants; 9 healthcare workers and 4 patients.

From our facility most often, the folders go missing. So they give lots of duplicate to us. So it's very difficult to get the medical history just from the patient itself because they don't even know what they're on. So even that makes it very difficult. It's an everyday thing. It's not just a once a month thing. Something that we have to deal with every single day. Where patients don't have their folders and even getting information from them is difficult.

Doctor G

Participants describe the loss of folders as a frequent occurrence which, as mentioned in Theme 1 affects all downstream processes. Doctor M reported that loss of records occurred 2-3 times a day. In the context of patient numbers, this translated to 5-7.5% of folders being duplicated on a daily basis. Staff who had experienced working at other facilities, such as Nurse Z, confirmed similar problems at those clinics.

While aspects related to information and its effect on workflow were previously discussed, I will now expand upon the experiential aspects related to the consultation as described by the two groups of participants. Participants describe the consultation as an interaction mediated by the folder containing the health records. The record grounds the conversation and gives perspective on the current presentation. The loss of a folder results in a break of continuity of

care built up from successive presentations and the summation of health management established up to that point.

When a folder goes missing it becomes problematic, a temporary folder gets opened up for the patient. In that case it becomes very difficult. It's a global problem since we don't have a booking system the same doctor doesn't see the same patient all the time so continuity of care is broken. If you have a patient with an extensive medical history with diabetes, hypertension, and epilepsy who has been on medication for years and their old folder goes missing you don't know where to start.

Doctor A

Inherent in the statements describing the loss of records was a certain amount of despair and frustration by doctors and patients. Years of participants' efforts were lost. Participants' expression of acquiescence that the loss of records was a part of daily clinic work was noteworthy. As part of their daily routine, they had to find ways around this impasse in order to manage their patients. These methods while quite creative, resulted in time wastage and inefficiency. These methods will be described as they are seen by the participants to be part of the experience of health records in their current format at Vanguard Community Health Centre.

As described by Doctor A, the problem relates to commencing the process of re-establishing the patient's background. Participants report that this process has to be undertaken with consideration of the patient's current presentation, the measurement and variation from normal of that day's vital signs and biochemical parameters and the urgency imparted from aberrancy. External factors described by participants include time pressures and the number of patients waiting in the queue to be seen. Essentially, the medical staff would use that day's snapshot to make a decision for future management, or management at least until the next consultation. Participants report that this would mean bringing patients back earlier, resulting in a greater turnover and hence, increased workload on the clinic. While these factors are not

ideal, they give an insight into the workings of the clinic and factors impacting on quality of care (this will be covered in more detail in Theme 3).

The method that seemed least complicated and, from an outsider's perspective, obvious, was to simply ask patients their medical history if the folder went missing and a duplicate was created. However, participants contended that for the Vanguard demographic, this process was not very useful and yielded little information. Communication with patients seemed to be problematic for a number of reasons.

They come in with a folder that has one piece of paper in it with nothing on it. And they go 'they can't find my folder doctor'. And I say 'dear'. And I have to start from the beginning. Full history, full examination and try and suss (sic) out what medication they are using. Which is usually the most difficult part. They can tell you what's wrong with them but the problem comes in where you have to discern what medication they're taking. That's a big problem.

Doctor B

Participants described that patients had varied understanding of their medical conditions and linguistic ability to relate this information. Therefore, the inability of patients to adequately communicate information related to their conditions can either be ascribed to their understanding of medical terminology or the communication of this information to the practitioners in a way that can be understood. Cultural, language and educational differences were seen to influence these expressions. For example, hypertension is translated directly into 'hipertensie' by Afrikaans speaking residents of Bontheuwel or called 'blood pressure' colloquially, while diabetes is simply called 'suiker.' Alternatively, Xhosa speaking patients refer to hypertension as the 'ihayi-hay.' Understanding these vernacular nuances, participants report, aids in the process of communication in the absence of the record.

As alluded to by Doctor B, participants reported that in the absence of the health record, ascertaining the names of medication from patients is more difficult than merely finding out their clinical conditions. From the patients interviewed, only one knew the names of her medication, while none knew the doses. Participants reported that patients often described their medication by appearance, number of tablets taken at a time and frequency of intake.

Then I had to explain to the doctor what medication, more or less I didn't know all my medication names, but I practically had to explain what medication I am taking. Yes, but they said I must bring all my tablets with so that they can see what medication I am taking... It's difficult when they lose your folder, because all your information is in your folder, you understand?

Vanessa

Participants reported the detective work that they had to perform in order to gain baseline information from patients. Depending on the scenario and as mentioned to earlier, the urgency of the presentation, patients were asked to go back to reception to find their original folder. If that was unsuccessful, patients were taken to a purposefully made *bricolage* board made of empty chronic medication boxes, which provided a visual cue.

Then we start with the fishing process, so we take them to the club room see if they can identify the medication and most of the time they actually can't although they give you a rough idea if they take it once or twice a day. Its pink and blue and you try to work around. If they can't tell you then what I would do is keep their folder in my room and would make them come back with the actual tablet packets with them.

Doctor T

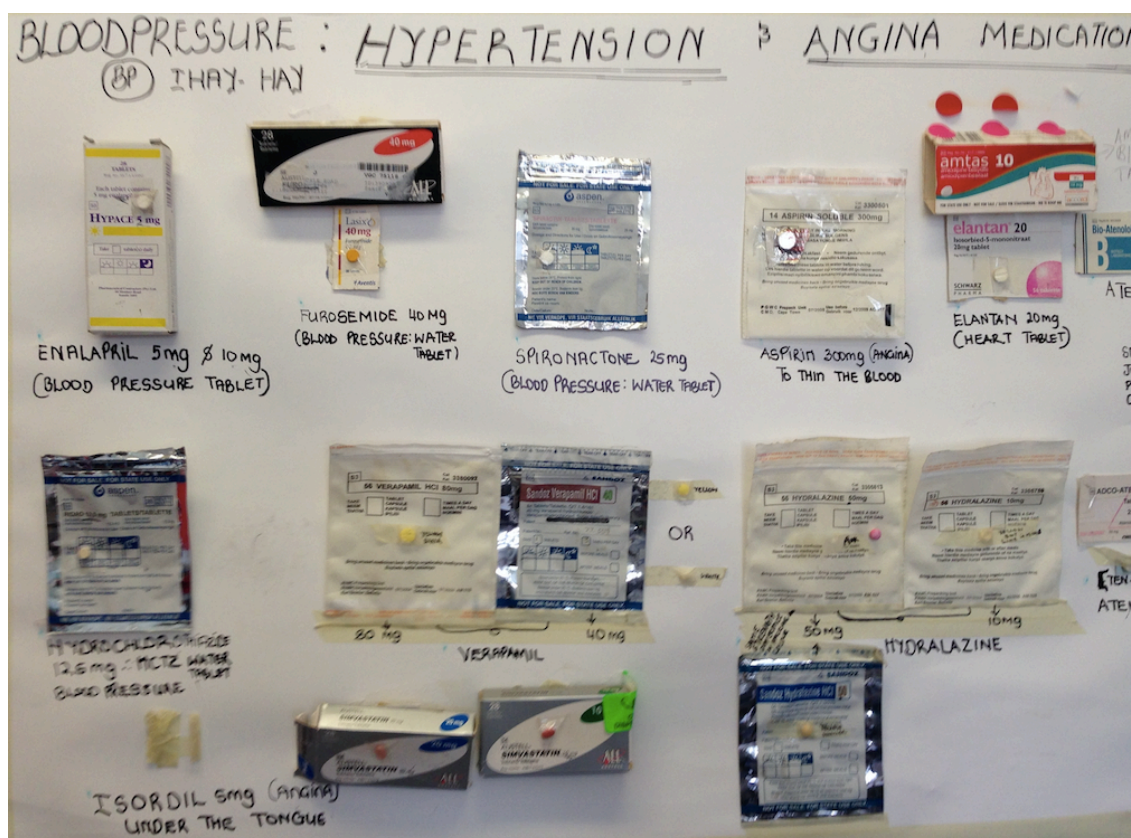


Figure 4.2 Bricolage board of chronic medication

The majority of medical participants reported bringing patients to the board to establish the names of their chronic medication so that a new prescription could be accurately written up in the case of expiry of the old. Participants put forward that the board was originally created as patient described their medication by the size of the tablet or its colour rather than by name or dose.

Most often if the patient cannot say what they're on or what medical problems they have. I usually send them home to fetch the medication... That's the most easiest thing... And as you know the medication changes like every month. So a pink tablet this month will be a white tablet next month. They don't actually remember or try to remember the name of their tablets but they know the colour of their medication and the box colour instead of remembering the name. So with them it's difficult because most often they don't know what medication they're on. So I have to ask them to go back home go get the boxes and kind of work out from there.

Doctor G

Interestingly, the observation that patients were not able to recall the names of their medication was prevalent regardless of duration of treatment. This visual dependence is typified by the following statements:

But if you bring the boxes here, I can tell you this is mine, this is mine.

Mhlabane

I don't know the name but I will know when I see the boxes.

Ntomnovuyo

However, Doctor B reported mixed success using the charts especially in the case of changes in prescribed medication, modification of packaging by pharmaceutical companies, or changes in supplier tenders resulting in a new company providing medication to the Department of Health. What was once a blue pill in a pink box may now be oval in a white packet. While far-removed from evidence-based best practice, the presence of this board is indicative of the frequency of lost health records and the scale of the problem associated with paper-based records.

If this method proved to be ineffective, the majority of medical participants concurred that patients were given two options: they could either go home to fetch their medication boxes on that day, or if they had sufficient medication, return a few days later for a repeat prescription. Doctor R reported that this however was not a foolproof method of finding out the patient's medication, commenting that on the patients return, sometimes neither the original nor the primary duplicate record are found.

While for some this may be an inconvenience, for others, returning may not be possible. Participants describe that they sometimes do not have a taxi fare for a return visit to the clinic, making these situations untenable. While for some, financial constraints may be the only limitation, for the elderly, participants describe a conglomeration of compounding constraints that affect their medical care in the case of a missing record. Doctor T observes that elderly patients are often affected by cognitive and auditory decline making questioning

difficult. They struggle to walk to the preparation room where the medication identification board is located. Once there, diminished visual acuity makes this process challenging as well. Junior medical participants point out that in the time taken to see an elderly patient whose health records have gone missing, they could see up to 6 patients.

So if they're elderly we really have to make an effort to sort it out. Because they can't come tomorrow. Then you have to walk with them to pharmacy to try and get tablets, show them. Is it this one? Are you sure? How many times a day? So that in total can take up to 20 minutes. It's easier if they are on one tablet, then you can walk them to the club room.

Doctor T

The loss and subsequent creation of new folder has resulted in the creation of multiple health records for individual patients, such that the patient's information is divided into numerous scattered sections. Patients may have four or more records at the facility. So while there is a greater chance of a record being found, the patient's information will always be incomplete at any given consultation. Ayesha describes this peculiar scenario of parallel records:

I have four folders here...when you go they don't find your file, and then you come again and they find your file. Then you come again then they don't know which file it is, then they find it again. Then you are a sick person... then they supposed to help you. Then the doctor gets 'front' but it's not his fault.

Ayesha

As the medication box identification board has its limitations and sending patient home to collect their boxes is impractical, patients were recently asked to bring their medication boxes to the clinic in anticipation of their records not being found. Participants observed that whereas local patients take some time to get used to bringing their medication boxes to the clinic, those originally from the Eastern Cape do this as a matter of course. From the descriptions given by participants, it is apparent that this practice of bringing medication

packets and boxes to the clinic is an established, socially acceptable practice in the Eastern Cape.

The frequency of missing folders, inconvenience of returning home and bringing a bag of medication to the clinic has resulted in a decreased reliance on the local facilities health record as the sole storage device for important medical information. Other forms of bricolage, albeit of a low technological base are reported to be used for storage and communication of important health information such as medication conditions, medication and dosages.

In the absence of health record system improvement from management, participants have begun handing some responsibility for the safe keeping of information over to patients. Three of the medical participants communicated that they recently began asking patients to write down their list of medication, store it at home and bring it back to the clinic upon follow-up. Doctor B improved this system, with the observation that while patients may lose or forget random pieces of paper, they give significant importance to the appointment cards and ‘hang onto these cards like they’re gold.’

Doctor B describes that as the clinic does not have an electronic appointment system, the appointment card give access to patients’ entry into the chronic disease club as opposed to the general outpatient department, where the queues and waiting times are longer. In the absence of the folder, participants report that the information gleaned from these sources saves time for both the practitioner and patient.

Another system that was beginning to be used at Vanguard CHC at the time of my research was the practice of giving patients a copy of their prescription sheet. Known as a CDU, the Chronic Disease Unit prescription sheet is used throughout government run primary care facilities in the Western Cape. While single-issue prescriptions are written on a lined sheet and kept in the folder, the CDU is filled in quadruplicate with copies given to the pharmacy, referral center in the case of transfer of care and to the patient herself for monthly collection of medication. Participants describe that while it is often used as a discharge summary from secondary, district or tertiary care facilities as it contains information pertaining to conditions, investigations and prescribed treatment with duration, they began using it as an adjunct patient held record to mitigate the effects of missing information.

So they will try to get an old CDU script. But there is the recommendation that the patient actually takes the fourth or third duplicate and keep that on them. And we have spoken to our pharmacist, and she has said that this is a system which they are starting to implement but we will only see the effects later on. It will take months before every patient has a script.

Doctor A

The benefits of this innovative system relate to its simplicity to implement. While the gains are likely to only be actualized after a few months of use, the CDU sheet needs to be completed as standard procedure in any chronic care consultation. Therefore, system enhancement is achieved without any change in workflow or creation of additional administration burden. As a result, barriers to adoption are negligible.

Thus far, this theme has covered the use of health records as a means of information and communication within Vanguard community health center as an isolated institution. Certainly, as a functional unit within the greater public health system, internal processes and efficiency are important. However, the clinic is in a dynamic state of interaction with referral centers, New Somerset Hospital, a secondary hospital in Green Point, and Groote Schuur Hospital in Observatory. Participants describe that patients are transferred for inpatient admission and specialist care at these facilities if the severity of their condition warrants transfer.

I was at Groote Schuur, it's a history, a long history. The difficult thing is that I can't go straight to Groote Schuur, I have to get a doctor first to send me to Groote Schuur, I have to go to a doctor first.

Charles

As described by Charles, Vanguard CHC, as a primary care clinic acts as a gatekeeper, transferring only when clinically indicated. Upon stabilization of a condition, the patient is transferred back to the clinic for future management as directed by the specialist centers.

Vanguard clinic also accepts and transfers patients to other primary level facilities in the event of local relocation or interprovincial migration. Accordingly, communication between facilities transpires for continuity of acute and chronic care.

The only thing I know is that if I'm there they'll give me a letter for the physiotherapist this side. That's the only communication which I've got. And then when I come here I can't give the letter to anyone. I have to wait and see the doctor, give the letter to the doctor. And to see a doctor is difficult. You can't just come in and see a doctor.

Charles

Referral letters mediate communication between facilities. In acute and emergency transfers these are held by the paramedic crews, while for specialist clinic up-referrals and down-referrals back to Vanguard, the letters are entrusted to patients to transmit. As a source of information and means of communication, these letters are part of a patient's documentary narrative health record.

Movement of patients between primary care facilities can take place with or without the knowledge of clinic staff. Participants Adele and Ntomnovuyo report having coexisting folders at Goodwood and Langa clinics respectively, where they sometimes seek care. These parallel non-communicating information streams can be detrimental to patients' health as clinicians should have access to complete information for accurate clinical decision making. Formally, participants report that patients should access care at a single primary care facility. If a patient requests to move to another facility, participants report that information is transferred so that continuity of care is uninterrupted. Two forms are recognized by participants.

We have to ask reception to transfer the folder. So sometimes the folder doesn't even get to the other clinic. They normally transfer by the driver. Most often, the folders don't get to the other facility. So that is why we have to write an in-depth letter to let them know what they're on. But I don't know why they actually don't give it. I should

actually ask them as to why the patients cannot have their folder. Maybe it's for medico-legal purposes. Maybe.

Doctor G

As stated by Doctor G, referral letters are compiled detailing patients' history, investigations and management to date as a point-form summary. Doctor T, being a recipient of similar letters from other facilities acknowledges that they provide a useful explanation of patients' clinical histories and saves her the task of using bricolage techniques to ascertain crucial information. On the other hand, participants recognise that the quality of the referral letter is doctor dependant. They observe that while future management aspects are often not covered, they provide a starting point for ongoing care. Participants describe that for primary care facility reassignment in the case of patients relocating, provision is made to have the health records transferred as well, in addition to the referral letter. Participants describe that they contact archives and assign a destination to the record. However, they do express some doubt as to the efficiency of this process. As such, the patient-held referral letter serves as a backup copy.

Comparisons can be drawn between this system and the internal use of the CDU prescription as an ancillary system for the storage and transmission of information.

It's awesome, I think that's it's good that you have something to work from. And some of them actually come with a whole folder. Depending on where they come from. If they come from Frere Hospital, they come with a whole folder. And you are like why are you carrying your CT scan results? But it's very informative. If we could adopt the same system it would be great.

Doctor T

Another system, not in official use in the Western Cape but drawn from a similar, if not more financially constrained environment, is the use of an A5 lined book by patients from the Eastern Cape to record their information. Informally described by participants as the 'Eastern Cape bookie,' this primitive patient-held record is often brought to the facility by patients from this province on their first encounter with local health services. Participants describe it

to be of great value. The Eastern Cape health book will be discussed in more detail in Theme 6.

Related to the theme of information and communication, are subthemes of privacy of sensitive information and patient confidentiality. Participants' experiences and opinions were explored in the context of current record keeping practices as well as those related to formats for improved patient held records. From a methodological perspective, while participants would not have directly experienced conceptual future format records, their experience of the current can be used to contextualize the latter.

Participants acknowledged that those involved in the handling, storage and retrieval of health records had a responsibility to protect the privacy of information. All participants expressed their trust in the current system of record storage. Ayesha reported that, "cause they have a policy of confidentiality, they not supposed to talk out."

Contrasting the responses of medical and patient participants proved to be interesting. While doctors held a paternalistic and perhaps theoretical view concerning the privacy of patient information, the majority of patients themselves were far more pragmatic.

Well I mean there's nothing so (emphasis) personal that, I mean I wouldn't mind. If somebody found my stick and accessed my information there is nothing they can do with it. They can just throw the stick away. Then if you come to hospital, they can't do anything with it. There is nothing so personal in there that they would need.

Vanessa

Like Vanessa, the majority of patient participants described an acceptance that while they owned the information in the medical records, which were stored at the clinic, intrusion on their privacy did not have any material effect on them. They expressed unanimity in the view that while access to information had to be balanced with the possibility of intrusion, the benefit of the former was more consequential than the transgression of the latter.

Everyone inside here must know where it is positioned. No, what can they do with your information? There's a lot of files there. If you look for a specific file then

there's a story to tell. And if you have your file at home then you are a dead person. Because how can you help me now? Clifford where's your file? Your file is not here. We check on the computer and the file is here. When I come to the emergency room and you trace my file they may not have the file. And it's safer here then at home... This is facts. Because at the end of the day if you give me the wrong tablets you're going to say, now I have to stand for you because someone took his file away.

Clifford

The leaning toward pragmatic utilitarianism also extended into the possible use of electronic health records, with participants emphasising that there is no difference between the unauthorised viewing of paper-based health records and hacking into electronic medical records. Again, emphasis was placed on access over confidentiality.

In the context of patient-held records, medical participants brought up the topic of stigmatized disease and its possible impact on patient uptake. While I can present their views as an informed third-party perspective, they could not be corroborated by the patient participants. The City of Cape Town's Health Research Committee's conditions of access to the clinic limited the researcher to the chronic diseases club. As such, the experiences of patients with stigmatized psychiatric or sexually transmitted diseases could not be solicited. Medical participants generally felt that there could be more resistance to the use of personal and electronic health records by those with HIV, tuberculosis, sexually transmitted diseases and psychiatric illness, than chronic lifestyle disease sufferers. However, they cited the example of patient-held cards used by HIV and tuberculosis patients which documented their positive status, CD4 (cluster of differentiation used as a marker of disease progression), medication regimen and clinic attendance. Participants believed that the accepted use of these cards has set a precedent for patients taking control of their health records. Issues related to secrecy, safe storage and disclosure to family members has therefore been introduced into patients' lives by the presence of these cards, enabling social acceptability.

It's the patient's responsibility who they disclose to and who they don't disclose to.

They get a card if they are HIV positive which has their CD4 count on it. They go home with that. Whether they leave that lying around or not it's their responsibility. If

they have TB, they get a card which has their treatment regimen on (it) that gets ticked off when they come to the clinic. What they do with that is their responsibility.

Doctor B

Participants also expressed the view that patient-held records can play a role in the destigmatization of disease. Rather than hiding diagnoses from family members, patient-held records can serve to legitimise disease by bringing them into the public sphere, mediating the process of disclosure.

People shouldn't stigmatize disease and in order that we get rid of it we need to speak about it. We need to become aware of it. No one is going to hide the fact that they are diabetic. So for that reason, they should not hide the fact that they are HIV positive or that they have got TB. If we stop stigmatizing it, they will as well.

Doctor B

An example of the institutionalized stigma at Vanguard CHC is the presence of the HIV clinic as a separate, prefabricated structure behind the main facility. The distance can be seen to be both physical and figurative.

4.2.2.1 Conclusion

The health record communicates the summation of clinical management built up from successive health seeking episodes to the point of current presentation. Furthermore, they ground the consultation into the patient's contextual reality and provide clinicians with a perspective on the patient's health status. The quality and availability of these notes impacts upon patient care in manifest ways. Findings suggest that retrieval of records at Vanguard CHC are not optimal and results in time and resource inefficiency. Not uncommonly, patients have multiple health records within separate health facilities resulting in incomplete information being obtained. In the absence of documented records, patients are often unable to communicate their conditions adequately for continuation of care to proceed. Bricolage techniques are currently employed to mitigate this issue. Amongst these is the entrustment of responsibility to patients for ancillary storage of their health information. Acceptance of this

responsibility is said to be gradually improving with participants embracing a pragmatic approach to balancing confidentiality with access to health information.

4.2.3 Theme 3: The interplay between health records and the quality of patient care

This superordinate theme is an amalgamation of 8 subthemes, comprising the expressions of 15 participants and was generated from 50 citings within the original data set.

The previous two themes have established the health record as a pivotal part of the clinics workflow processes, as well as a source of information and communication. Effectively, the health record contributes to the patients' perception of the quality of care and general experience of the clinic. With reference to the cycle of interactions (figure 5), folder retrieval is the third step in the process of accessing care. The inability to access the folder therefore results in delay or prevention of access to care.

First of all you must sit in front and they call your name out and they give you a folder so you can see a doctor. So I never come out by the doctor. Because my folder was now ma lost. You have to have your folder. If you don't have a folder... They won't help you without a folder.

Adele

The resultant frustration has an effect on the patient's experience of health records and the clinic in general. Negative experiences described by the participants resulted in them delaying their presentation to the clinic. Both Ayesha and Sophie described that they would wait for up to 4 days before eventually deciding to report to the clinic for medical care. Delayed presentation can possibly result in worsening of the severity of clinical conditions, especially with underlying comorbid conditions such as diabetes and HIV.

Previously, I had described aspects related to loss of continuity of care with the loss of folders and clinical information in the chronic club setting. Participants described the

experience of not being able to access after-hours emergency medical care due to missing folders at the clinics 24-hour trauma centre.

One time it happened already, ohhhhhhh...I had to come here late at night, so they said I must come again because they can't find my folder. Don't know what did they do with the folder. I am diabetic and my blood was high. So I came here and they said I must come back in two days because they couldn't find my folder. I was really sick.

Adele

Worryingly, similar scenarios were experienced by other participants. As access to emergency medical care is a human right, this experience if accurate, would constitute gross medical negligence. Adele's experience of being turned away left her with a negative impression of the clinic's ability to care for her and resulted in her request to take her folder home with her to prevent similar future occurrences. Besides preventing patients from accessing medical care, missing records result in patients being converted from chronic to acute-on chronic sufferers with the loss of continuity of care. Multiple participants reported that when records go missing and patients are clinically unstable, clinicians' management cannot be grounded in previously efficacious therapeutic options. Therefore, doctors' ability to treat effectively is curtailed. This stressful situation is described:

I think you do what you can at that stage. What is his blood pressure? What is his sugar? What does he know about what he has? If he can tell me he is diabetic, has been on two or 3 three agents? It makes it easier. If you have someone who can't tell you oh no I don't know which tablets, I don't know how many tablets, I don't know how many times a day I have to take it. What do you have in front of you? You may have to start him on whatever. Or restart from scratch. If he has a sky-high blood sugar or blood pressure, then try and stabilize that. Then come back in two weeks...

Doctor M

Participants describe this uninformed choice of therapy to be detrimental to patients' health. Nurse Z announces that, "you assume and prescribe whatever." Incorrect and inadequate

dosing, adverse drug reactions and worsening of target organ damage can result from this hazardous form of medical care.

I've got some tablets for shoulder that is very painful. I didn't know that the tablets which I have already taken is clashing with that. With that tablets. And I didn't know what was wrong with me. I thought that it was something new to me. I was sitting outside the shopping center and the next minute I didn't know where I was. My mind couldn't register where I was.

Charles

Charles' vivid description of an adverse drug reaction took place as a result of interactions between medication prescribed at Groote Schuur Hospital and Vanguard CHC clashing. He claims that the clinic doctors prescribed medication without cross-checking previously prescribed medication as they did not have access to that information. Vanessa, who had a good understanding of her conditions and medication, reported having to check her medication at the pharmacy to ascertain that the correct medication was prescribed. Not knowing the names, she could not ask the prescribing doctor, and subsequently had to wait for the boxes at the pharmacy to confirm their accuracy.

The failings of the system did not go unnoticed by the patients. They expressed their lack of faith in the health system, partly related to experiences with missing information.

Yes, and another thing to you go to different doctors every time, now this doctor will say no this is wrong with you, each doctor has their own opinion, you understand, so if it's on their folder, this doctor said ABC and ABC it's not. And another doctor will say I find it's DEF. Some of the pages go missing especially in that system there, they don't know what is going on then they just diagnose you with whatever they think is right.

Vanessa

Participants' loss of trust in the clinics perceived inability to adequately provide quality care and inferred causation by patients that missing information from health records was to blame, demonstrates the problematic nature of the current system and its need for improvement.

Ayesha, who has four folders at the clinic reported that she would rather be seen by a private general practitioner as she could be rapidly evaluated without the need for, "go there and find out that and go there and find out that" which came about from clinic doctors not having sufficient information upon presentation. Another significant cause of patients' loss of trust and perception of poor quality healthcare is the process of sending patients home to collect empty medication boxes. Participants report the difficulty in returning up to two weeks later to receive a new prescription.

Health records are also described by participants to impact on the quality of the consultation and their effectiveness in addressing patient concerns. Overburdening of the system due to the large patient load, bringing patients back with their medication boxes and unawareness of evidence-based best practice protocols are cited by participants to place time-pressure on the length of the consultation. Doctor T observed from her experience that the quality of records and possible absence impacts upon the time taken to see patients. Poor quality, unordered records with missing information results in her focusing her attention on re-establishing basic information, rather than giving time to understand patients as holistic bio-psycho-social beings.

You spend so much time trying to sift through what condition the patient has, what medication they're on, what has been done before, where to go through now. By the end of which, you only have 5 minutes left to examine them. You want to spend less time taking a history and everything should be there. You want to take a good examination and find out why they are there today. So the quality of the consult can be a lot better. By the time you sift through what medication they on, the diagnosis and everything, it takes long.

Doctor T

Participants describe that the interactional, healing nature of the consultation is limited to a mechanistic, damage-control fact-finding mission to stave off complications rather than improve health. Participants observe that more time is spent interrogating the records than listening to and empathizing with the patient's condition. Charles observed that to save time, doctors would limit him to one complaint. Therefore, he had to decide which of his complaints affected him most, expressing, "that's the difficulty if there's another problem."

Prof H questioned the health systems drive to maximize quantity over quality of patient consultations, stating that this process led to a vicious cycle of ever-increasing numbers and decreasing quality of care.

This is now the first time that the doctor examined me... At least now for very, very long time... And here not actually they book you on and write down and give you your medicine... Yes it's a problem. Because sometimes like one doctor, my blood pressure is high, but it's never like high. And now the thing is this, you can go home but she didn't examine my heart. She did do it today. So you go now home and the night or tomorrow morning you get a heart attack...

Adele

Confirming Doctor T's statement regarding the time limitations for patient examination, Adele describes her experience of not being adequately assessed by her doctor. She also describes her fear of having a heart attack, which the therapeutic consult did not allay. The combination of presenting a single symptom and only having a cursory examination performed can result in missed-diagnoses, late and multiple presentations further increasing the burden on the clinic and diminishing patient's perception of the quality of care provided by Vanguard CHC.

Management decisions which influence the use of resources for investigations and therapy are also affected by the absence of information from the health record. Unnecessary investigations and follow up consultations can occur resulting in frustration for both the patient and doctor.

Well I think it's very frustrating for the patient, and for the health provider both, because you don't have enough information to treat the patient adequately, especially if patients have been here several times, have had investigations and are seen by a new doctor who doesn't know what's going. And often they are not educated enough to explain what's going on with them. So I'm sure it's very frustrating as it delays several processes, and makes you do unnecessary investigations again. It causes a lot of issues, definitely

Doctor E

Supporting this view, Doctor T expresses that as she often does not know what was previously done for the patient, she would repeat tests or actively manage conditions which were for palliation, giving patients false hope and creating confusion for clinicians later on.

4.2.3.1 Conclusion:

Health records contribute to the quality of patient care provided by the clinic. They establish a baseline from which clinicians can advance continuity of care. In their absence, basic information has to be re-established, wasting time and resources and restricting the quality and healing nature of the consultation. Incomplete documentation limits patients access to adequate emergency care and can cause clinical deterioration from chronic to acute-on chronic disease. Dissatisfaction with service provision was expressed by both doctors and patients. As a result, patients delayed their presentation to the clinic with some requesting control of their health records.

4.2.4 Theme 4: Emotions associated with the experience of health records.

This superordinate theme is an amalgamation of 14 subthemes, comprising the expressions of 14 participants and was generated from 69 citings within the original data set.

Negative emotional expressions predominated in participants' experiences of medical records. These include anxiety, dissatisfaction and frustration, with the former most

emotively expressed and the latter most frequently described by participants. Reporting on the expressed sentiments and determining the causative factors can inform areas of dissatisfaction with user experiences of current record keeping practices. In the same way, addressing these factors can result in genuine improvements for future models.

While general anxiety in the clinical scenario of ill health is a common finding, inefficient use of health records was described by participants to worsen this emotional response. Participants described that the uncertainty of finding their records at archives resulted in consternation for a number of reasons. Firstly, its loss or duplication meant that they had to wait longer to access care. Thereafter, they feared that their difficulty or inability to remember the names of their medication resulted in doctors becoming annoyed or irritated with them. As described in theme 3, participants reported their fear of adverse health consequences due to inadequate care ascribed to brief consultations and superficial examinations.

Post consultation, participants described that they often did not receive sufficient information on new or advancing clinical diagnoses for them to gain meaningful understanding. They expressed that doctors spent more time writing than explaining, leaving them uninformed and anxious. Often, there was not enough time for detailed questioning, or patients were too afraid to ask. As patients were not allowed to take their folders home with them, the fear of unknown prognoses and sense of foreboding associated with actual or perceived bad news created unnecessary anxiety.

Say for example you got a tumor, or whatever, you understand and this can happen and that can happen, she is writing it all in her notes, and you go home and all you thinking about is this tumor. You're going to die, You're going to die. You're going to die. Meantime in her notes she has written if you remove this tumor then there is a 90% chance of survival. So it will all sink in slowly... You not even listening to what she is saying. You not even taking it in... Your pressure's sky high and your sugar's sky high because you have a tumor... And maybe it's just this little thing and suction it out or whatever. And then you realize you are panicking for nothing.

Vanessa

Vanessa pointed out that if she had a copy of her notes, she would be able to interrogate them over time, allowing her to ‘digest’ bad news slowly. She expressed that currently she does not remember enough of her consultation and the explanations provided by doctors for her to communicate updates of her conditions with her family and doctors in the future. As such, like other participants, she feels that her fears were not adequately addressed and therefore felt unsatisfied with the experience of healthcare provided at the clinic.

Ayesha expressed similar sentiments, stating that with the loss of information from the folder, she was repeatedly called back to the clinic for follow-up consultations a month apart causing her to worry about the severity of her condition. This waiting was exacerbated by minimal interval communication from the doctors.

Ntomnovuyo’s fear of a harsh response by the Langa clinic counselor to her non-adherence to anti-retroviral medication after her folder went missing led her to delay presenting to the health facility for care. Subsequently, she sought assistance at Vanguard CHC on the basis that she was not known to them. In her case, presenting to the clinic after loss of information was associated with the combined anxiety of the place itself and the clinical consequences of non-adherence to antiretroviral medication.

Frustration was frequently brought up by participants in their experience of health records at Vanguard CHC. The majority of participants’ complaints related to emotional experiences of themes 1, 2 and 3. This being frustration with workflow processes, communication and the quality of care both provided and received.

Both patients and doctors described the loss of medical records and incomplete information in the folder to be both frustrating and demoralizing. Furthermore, Doctor B described her attempts at bringing her concerns about the systemic inefficiencies in the storage and retrieval of health records to management as an exercise in frustration. Participants described that in the face of these insoluble workflow and communications difficulties, they had to persist as best as they could. The problem was perceived by the doctors more than the patients to be unintelligible. While patients were often creative in finding workable solutions to their frustrations, doctors felt that the systems which created theirs were insurmountable.

Frustrations stemming from problems inherent to the structure of the health records and its influence on workflow, communication and quality of care resulted in frustration and tension between health workers and patients, with both parties feeling aggrieved by the behaviour of the other.

4.2.4.1 Conclusion:

The health record acts as an intermediary in the medical transaction between the doctor and patient with ineffective use described to create negative emotional responses such as frustration and annoyance. Patients object that doctors give more attention to the record than them and limit the number of complaints they can advance. They are often unable to remember and later communicate substantively the advice given to them at the end of a consultation. Needless anxiety stemmed from over-interpretation of symptoms by patients with inadequate counselling and placation by health workers. A hard copy memorandum documenting salient features of the consultation may assist in relieving unnecessary anxiety by allowing patients more time to interact with their health information at their own pace.

4.2.5 Theme 5: The role of health records in patient education, empowerment and the ownership of disease.

This superordinate theme is an amalgamation of 14 subthemes, comprising the expressions of 18 participants and was generated from 131 citations within the original data set.

This theme explores the mutual experiences of doctors and patients with one another as influenced by and mediated by the health record. I will present findings which suggests that the health record plays a role in influencing the behaviour and perceptions of doctors and patients towards the other. Exploration of these factors is fundamental to understanding dynamics related to social status, hierarchy and power inherent within medical consultations between unequal parties. If accurately identified, these inequalities may be mitigated by improving or augmenting the current health record system for patient empowerment and enhanced continuity of care.

This theme will follow the narrative of doctors' experiences of patients' relative states of empowerment in the context of fragmentary, incomplete or missing health records.

Thereafter, patients' experiences and perceptions of their role as partners in the medical consultation within the context of information paucity will be explored.

Lack of understanding...unfortunately patients around here, responsibility is not a big thing. They don't take responsibility for anything. Not their health. Nothing... And how to overcome it? Emphasis. Emphasis. Emphasis. Education. Education. That's all we can do. There's only so much you can do.

Doctor T

The presence, absence and quality of contents of medical records was described by the majority of medical participants to influence their experience and perception of patients, disposition towards them and consequentially, the quality of care delivered in the therapeutic consultation. Understanding, education and responsibility of care were cited by Doctor T and corroborated by other participants to significantly affect the practitioner- patient experience and relationship. I will provide phenomenological evidence of the health record as a dynamic actor within this network of relational experiences and its role as a possible source of patient empowerment.

As mentioned in theme 4, the health record has a causal relationship with emotive experiences, namely anxiety and frustration. In the context of substandard quality of notes or their absence, medical participants described that they felt that patients should have the relevant knowledge of their conditions to fill in the information gaps. Unfortunately, this was rarely the case.

Like this patient knew that she had TB but she didn't know, no she knew when she completed treatment but it took a long time to let me know, which was what I asked her in the first place. Were you getting the medication at Vanguard or at Langa? She didn't understand what I was saying and I couldn't just ask someone else especially with regards to TB and HIV because I couldn't just ask someone to interpret for me.

Doctor R

Doctors described that patients depended on the health record as the sole store of their clinical information. This reliance was experienced by practitioners to be a demonstration of patients' lack of responsibility towards their own health. Furthermore, they commented that the physical action of handing over the medical record at the beginning of the consultation was tantamount to handing over complete responsibility of care to the practitioner. While care may be the responsibility of health practitioners, participants expressed dejection that there was an overwhelming burden placed upon them with patients taking little personal responsibility for understanding their diseases; names, indications and adherence to medication; as well as an interest in the betterment of their own health.

So I try, especially since I've been here to empower patient to take responsibility for their own health. Which is often difficult because they often rely on you and they don't know what tablets they have been on even if they have been on it for years. And I find that quite frustrating because I feel that you should be interested in your own health to learn the names in case something happens and notes go missing. So I have been trying to reinforce that. But I suppose in a way things are happening I can see how the patients would give me your folder and expect you to take control of things.

Doctor E

As such, some patients are described by participants as being passive participants in the healthcare relationship. While this may be tenable in a well-functioning, adequately funded system with fail safes and redundancies, this is not the case in the Department of Health's services. Irresponsibility resulted in patients falling between the sparsely provided safety nets with participants commenting that it furthers chronic disease progression and increases the workload on an already overstretched system.

While the majority of medical participants described patients to be relatively irresponsible, there was a spectrum of responses relating to their current involvement and possibilities for future empowerment in becoming active participants in their own health. As Vanguard CHC did not have an active health promotion program, doctors contended that it was up to them to educate patient on their medical conditions. Their description of the success of their attempts varied.

You get patients who are interested and those who expect you to look after them.

These who just come in and don't have any idea what medication they're on. So I sit them down and tell them that at the end of the day they need to know what medication they are on and you need to know what you are taking it for. I'm here to advise you and help you but I'm not here to fix you because at the end of the day I go home to my family and you stay with your high blood pressure and diabetes. So if you don't start taking responsibility for yourself, it's never going to come right.

Doctor R

When looking at the experiences of practitioners, it was interesting to note that with experience, cynicism of attempts to educate patients grew. Younger doctors or medical interns professed with relative enthusiasm that reinforcement of educational messages would result in patient empowerment, while their senior colleagues, such as Doctor R above, expressed a more paternalistic and jaded approach to patient education.

I think with us it's just reiterating, if you continue to tell them to do something, they will do it. For example, with our chronic patients we have to really remind. The pharmacy wasn't giving out the MDI's without giving the empty pump. So they had to get it in their mind why must they do it. So every consultation we tell, please can you bring your MDI. They won't give it. And they actually like a couple of months down the line they tell people they not going to give it to you. If you remind people and telling them the reason why.

Doctor G

As there were stark contrasts in levels of education between the medical professionals and patients, it was not surprising to listen to doctors expressing their views of patients' lack of basic medical knowledge. They expressed that after years of taking the same medication, many were not only unaware of the basics related to their conditions but made no effort to question or find out more for themselves. In some cases, patients did not even know their own diagnosis. As a result, participants went so far as to say that patients were medically

illiterate. Altogether, doctors expressed that the combination of lack of responsibility and ambivalence to care prevented them from progressing in their self-education and empowerment.

Contrasting with the views of medical practitioners, patients expressed their feelings of unmet needs in the consultation. Their experiences were relatively at odds with those presented by medical practitioners. While doctors contended that patients were uneducated, unmotivated to empower themselves and lacked responsibility for their own health, patients claimed that medical staff were unwilling to listen to, or ignored their complaints, treated them poorly and did not spend sufficient time explaining to them their conditions so that they could gain meaningful understanding.

I had a couple of problems, because of the tablets they giving me, like pain tablets, your tummy is burning, so I mentioned. They hardly take notes, I am tell the doctor look here I am using it, I am telling you what's wrong with it. I'm telling you it's not working for me. I know what side effects it is having on me. Some people here think you stupid. My wife came here and she nearly died, she came here with tablets, and I told her why didn't you tell them it does not work for you. When she talk to them they ignore her and keep on doing. They can't tell you that because you're using the tablets and now she's downslope... I wanted to mention it there by them but they aren't going to listen to me.

Clifford

Like Clifford, Vanessa and Charles affirmed that doctors rarely listened to them, rather they spent more time interrogating the folder than they did the patient. Consequentially, their experience was akin to doctors treating the folder rather than the patient. At the end of the consult, patients expressed that they had insufficient time to ask questions and empower themselves. Rather than unmotivated and uneducated, most of the patients expressed that while they knew very little about their conditions, their circumstances did not give them access to the information required to educate themselves. Of the patients surveyed, only one had studied post-secondary school and was employed, albeit as a shelf-packer. Contrasting

this demographic to the highly educated medical doctors, it is easy to apprehend the poor opinion held by health workers of their patients.

When I come to Vanguard, not one of them has explained what is wrong with my eye.

All they say is that I'm giving you this medication, that medication. And there you go.

No-one has explained to me why is my sugar... they just put me on the drip, put me there and things.

Vanessa

Far from being passive recipients of health, some patients demonstrated their thirst for information about their conditions, their need to understand how their medication worked, and how their symptoms correlated with disease processes. Charles in particular maintained that while he was unimpressed with the treatment received at the clinic, his experience at Groote Schuur Hospital of being sat down by a doctor and "explained every little thing" set him on a self-empowerment trajectory by which he was able to understand his complex thyroid condition and further his knowledge with internet searches and the acquisition of related multimedia. At the time of his interview, he was able to independently titrate his medication according to his thyroid function biochemistry. Although his capacitation was remarkable, it was however counterbalanced by participants like Millicent whose lack of knowledge and apparent apathy towards her condition was striking. Seemingly, time spent providing patients with the education they require early on can yield benefits in their clinical course as patients are able to become equal partners in the healthcare relationship.

Yes. Sure I think so. Lots of patients have a desire to learn more about their diseases.

They just too scared to ask. Or they too frightened especially if we are rushed. A doctor can come over as very intimidating. So they rather keep silent. But I think most of them want. There are obviously the few who just doesn't care. But they made the effort to come to the day hospital. So obviously they want to know.

Doctor M

The views expressed by Doctor M were corroborated by many of the patients. These patients, such as Vanessa affirmed that they wanted to take more responsibility for their health, but

were unable to as they did not know enough. In fact, many felt intimidated to ask health care workers about their progress. Differences in education levels, language barriers and aberrant cultural precepts about medicine were factors which may have attributed to patients being viewed as unmotivated or uninvolved. Traditionally held respect for health workers as ‘healers’ contributed to the divide between patients and doctors. While patients such as Sophie placed unquestionable faith and much responsibility on the doctors’ health hegemony, others like Ayesha, Vanessa, Clifford and Charles being more vociferous and acutely aware of their rights as patients were more willing to question practitioners and hold them to account.

If they listen to us instead of working with us they here with an attitude of being the doctor. Be the person that you’re supposed to be. Because you must listen to us.

We’re using the tablets... You don’t tell me, I’m the doctor. But I’m sorry doctor, are you using the tablets? You think I have the problem. I can’t use that tablet. It’s not everybody speaking out like I do. They just take it and go home and the next morning they’re gone or whatever happened. It is a problem. You’re on the right... Because you can’t open the folders with the doctors here.

Clifford

Some participants expressed that their attempts at seeking health education were not adequately addressed by health practitioners at Vanguard CHC. Vanessa voiced that after being diagnosed with diabetes, her doctor simply told her that she should “watch her sugar” without further explanation as to how to go about doing this practically. She advanced that had she been able to view her record or had a copy, she would have been able to learn more and gain suitable insight into her condition. Patients suggested that the presence of a personalized health record would provide them with a physical testimony of their medical care, relevant health background from which they could empower themselves. This would provide the foundation upon which doctors could assess patient knowledge and understanding to provide targeted health education.

Paternalistic care was identified by health practitioners to be indispensable in caring for this population, taking decisions with minimal consultation. This was either because there weren’t

many options available, or they felt that given the educational gap between them and patients, they knew better and had the patient's best interests at heart. Most patients accepted this status quo unquestionable given the inherent respect the community had for the health workers. So while autonomy in decision making was not as much contested, patients maintained that they wished to at least be informed once a decision had been made on their behalf. In this way while empowerment towards taking autonomy for their health decisions was not as much a consideration, basic education concerning their health was an uncontested need.

So I think the doctor should explain to you why is your sugar high. Ask you what did you have for breakfast, what did you eat? And explain to you why is your sugar fluctuating... It's not for me to ask the doctor. That would also help, explain. You know doctors don't have time to explain to their patients anything anymore... The hospital's overcrowded they don't have time. And yet when you take an oath you have to make time for your patients... So you must treat a patient like your own child.

Vanessa

While patients sought some degree of paternalistic care, and doctors actively effected the role of the senior in the healthcare relationship, this dynamic is fraught with challenges. Patients had different capacities, relational expectations and propensities towards taking ownership of their health. Over or underestimating these individualistic peculiarities was cited to be prevalent given the large patient base which Vanguard CHC served as well as the lack of continuity of care owing to high staff turnover. Underestimation of patient capacity was reported to have been experienced. Patients expressed their sense of frustration when their attempts at self-empowerment were met with condescension or disregard. Clifford described his experience of requesting a written summary of his conditions from the clinic's doctor and the response he obtained:

There was a time when I thought I'd bring my book with and you'll write in my story. And he said why should I do that. He's trying to protect himself. Do you see what you're doing now? You're bringing things in that I've forgotten. I mentioned it ya. But they think I'm cocky. They say why should I do that. I say okay you don't want

to commit yourself like they do with my life. I don't talk about what I hear, I talk about experience.

Clifford

As experts of their own circumstances rather than their medical conditions, patients' need for education and empowerment is as great as the practitioners need to understand patients' capacity holistically. I have demonstrated that in the current system of facility based folders, the health practitioner does not have the time to adequately address the patient's needs for education about their conditions. Similarly, as patients are seen by a number of health care workers, continuity of care is spread over an ever-changing team, preventing relationship building and estimation of an individual's ability required to deliver targeted education and health promotion.

Furthermore, leaving the folder at the facility does not give patients a repository from which they can base their further self-education. The role of the folder as a source of responsibility and ownership may be tied to its location. The acts of handing the folder over to the health worker as well as leaving it at the clinic at the end of the consultation could translate into placing the onus of responsibility onto the physician and leaving responsibility behind until the following visit. The mismatch between the patients' needs from the consultation and the health care provider's ability to address these adequately within the context of inherent institutional hierarchical complexities may be levelled by changing the nature of the health record. This innovation will be addressed in theme 6.

4.2.5.1 Conclusion:

High turnover of staff at the clinic precludes long-term interpersonal relationship building between staff and patients. The presence, absence and quality of contents of medical records influences the experience and care delivered in the therapeutic consultation. Patient education, understanding, and responsibility for their health contributes to the practitioner-patient experience. The health record is a dynamic actor within this network of relational experiences and if correctly designed, may be a possible source of patient empowerment. Doctors view some patients as being uninvolved passive recipients of healthcare in contrast to patients, who while accepting paternalistic oversight, still wish to learn more about their

conditions. However, there is limited time during the formal consultation to adequately address health education and inherent hierarchical differences between these parties can be an impediment to inquiry.

4.2.6 Theme 6: Health record innovation.

This superordinate theme is an amalgamation of 21 subthemes, comprising the expressions of 17 participants and was generated from 113 citings within the original data set.

From the previous five themes, it can be conceived that health records play a considerable role in the functioning of a health establishment, the quality of care perceived to be provided and the relationship between the patients and practitioners. As such, innovative application of their development requires that these multifarious needs are met so that patient empowerment can be actualized.

Following on the phenomenological investigation of the experience of health records by participants, they were asked the following question.

“Given your experience of health records, how do you feel that they can be improved?”

The question was open-ended, non-leading and framed within the context of users experience of the currently utilized system. This theme will explore the responses related to informally used socially accepted precedents, conceptualized formats for future health records, as well as benefits and possible barriers to uptake of the various formats. Analysis of these factors are important in answering the practical aspects of this thesis and informing the formulation of guidelines for health record innovation.

Participant responses varied considerably. The spectrum ranged from the improvement of the archiving system to the use of cloud-based databases for the storage of health information. Importantly, the majority of participants proposed some derivative of patient held records as a potential advancement, citing examples of antecedent formats such as the discharge summary, paediatric road to health chart, maternity case record and Eastern Cape health book.

While the discharge summary was discussed in theme 2 as a bricolage form of health record, the Eastern Cape health book was frequently brought up by participants for its adaptive simplicity and prevalent use in the migrant Xhosa population.

But in Eastern Cape they have a book system, so they bring the book, but not all of them. The ones that don't then you have to start from scratch. So if it's a high blood pressure patient, you have to start from where their blood pressure is at that moment. I think it is helpful, because they carry their information, so you don't have to scratch your head. Where am I going to start? Everything is written in there.

Nurse Z

Participants described the Eastern Cape health book to be an informally used, yet prevalent method of maintaining continuity of care for migratory patients in a health system characterized by resource shortages and general inefficiency. These records are soft-cover lined A5 books purchased from stationery shops or general dealers. To save money, an A4 book may be purchased and cut into two halves. These records are an initiative taken by patients, fulfilling a responsibility to their own health. Participants observed that in some cases, it may have replaced formal clinic or institution based records entirely with contemporaneous notes written into the book from multiple clinics as well as during inpatient hospital stays.

It's awesome, I think that's it's good that you have something to work from. And some of them actually come with a whole folder. Depending on where they come from. If they come from Frere Hospital, they come with a whole folder. And you are like why are you carrying your CT scan results? But it's very informative. If we could adopt the same system it would be great.

Doctor T

This patient-held book system of record keeping was positively experienced by practitioners. While in some cases, it may have been an auxiliary to the clinics own records, in others they formed the only available documentation of the patient's health. As such, they were

perceived to be both informative and effective in their ability to transmit information, in the absence of other records, either due to loss or first presentation to a new facility. Another benefit espoused by practitioners is that they provide patients with a sense of responsibility and ownership of their health. Its value lies in its simplicity: as the book is unformatted, inputs are chronological, together weaving a cohesively intelligible narrative from different entries.

A patient-held summary of care record sporadically in use at the Crossroads Clinic on the Cape Flats is the 'smart-card.' Similar in nature to the Eastern Cape health book, the smart card was described by Nurse Z to be a cardboard based patient-held record denoting essential information in summary format.

Yes because the patients, they enjoy that smart card. They know that everything is there. Everything is there. Of all the day hospitals its only one which doesn't have a problem with reception. A problem with missing folders. If the folder is missing then you just go to the smart card, and it tells you everything... It works very nice and is easy.

Nurse Z

While the Eastern Cape health book and the smart card, although not officially in use formed auxiliary records to the formal institution based medical record, participants brought up two examples of patient held records provided by the Department of Health, whose use was prevalent in the public health system. These are the paediatric Road to Health Chart and obstetric Maternity Case Record. The difference between these and the previously discussed institution-specific folder based medical records is that the former decentralize storage and access, giving patients full responsibility to look after their own health.

In detailing the direction health records needed to take for improvement, participants described the requirements which novel records, regardless of format, ought to fulfil, and the benefits which meeting these needs could achieve. These related to needs that are unmet by the current system. In essence, they are a synthesis of the phenomenological user experiences detailed in themes 1 to 5.

Participants described that the primary purpose of health records is the ability to transmit information of successive episodes of health interactions possibly from multiple sources in a cohesive manner so that overall understanding is easily gained. Respondents contended that current record keeping practices did not meet this outcome for the reasons that information is often unavailable, incomplete or disordered.

It would definitely improve their health. It would improve the consult which are not necessarily the best but just in terms of frustration of not finding information that you need. So if I spend less time focusing on finding information and having the information there. It would definitely have a positive impact on your health. I'm pretty sure.

Doctor T

Indeed, participants described that a major improvement would come from having ubiquitous access to records. While effortless access is seen to be a fundamental requirement of health records, improvement in the structure and content of records was described to be a significant need.

I would like something that is after each other, like all the dates and visits must be set out. So I know exactly when last I was here and what was the problem So I want it to be more organized. And for the front, there must be an index. Like key words. Like the stuff is scrambled in the folder. The doctor has to go look back to what is what. Weren't you here already for this? So they know what tablets they give you and if it helped or not.

Ayesha

Participants described that when the folders were available, the contents were a somewhat random collection of clinical notes, prescription charts and results sheets loosely contained. Participants such as Drs B, R and T reported that while they were able to make meaning of these notes, clinical summaries would save time, "You spend so much time trying to sift

through what condition the patient has, what medication they're on, what has been done before, where to go through now.”

These views are in concord with the sentiments expressed above by Ayesha. The addition of a summary sheet and an index of previous episodes of outpatient care or hospital admissions were advocated by participants. They claimed that together, these would provide clinicians with an instantaneous impression of the patient's clinical background and baseline health status. Doctor L maintained that it would result in an increase in the quality of the consultation, as more time would be devoted to listening to patient complaints and completing a thorough examination.

You want to spend less time taking a history and everything should be there. You want to take a good examination and find out why they are there today. So the quality of the consult can be a lot better time saving, by the time you sift through what medication they on, the diagnosis and everything, it takes long.

Doctor T

Besides enhancing the quality of consultation, pervasive access to information was described by participants to aid in continuity of patient care. Not having access to clinical information resulted in patients defaulting medication and worsened control of chronic conditions. Also, in cases of emergency or when patients present to facilities other than their primary care provider, the absence of a documented health narrative led to ineffective provision of life-saving care.

Another requirement of health records put forward by participants is its potential as a patient education tool. Currently, patients are not permitted to take their records home with them. Without a physical source of reference, they are often unable to remember, reflect upon or report on previous episodes of care. My finding of the dependence patients have on clinicians for their health education and their limited resources for supplementary enlightenment reinforces the view that a health record accessible to both parties in the health transaction may be beneficial.

It will be easier for me to explain to you, and they can just check the book, this is Clifford's booklet. This is his problem. Then if he wants he can write a new story inside what I am coming for.

Clifford

Apart from the patients' individual health narrative, the possibility of using the health record as a means of providing population-wide directed health promotion was brought up by participants. However, these benefits would be contingent on alteration to the current model of unconnected, facility based record storage.

Well it works well with pregnant patients and mothers with the road to health card.

Patients are very good with keeping their appointment cards. Why won't they keep their own records? It's a bit more of a sense of ownership especially if there's health promotion in it.

Doctor M

Integral to the transfer of records from facility to population would be a relocation of responsibility and ownership of disease. A patient-held record was viewed by participants to do just that: allow patients to become more responsible for their own health by means of documentation of illness and education on cure. Instead of limiting patient education to a few minutes within the consultation, a new format patient-held record was described by participants to expand the process of self-education out of the clinic and into patients' lives.

Participants' responses regarding their preferences for the improved format of patient-held records can be divide into two groups: those who advocate the digitization of records, and those who felt that a paper-based format would be practicable. Both groups however, concurred that health records should be patient-held, advancing the benefits previously cited.

Participants advocating paper-based patient-held medical records included both patients and health workers, although the latter were in the majority. Interestingly, the descriptions of novel format records between the two groups of participants varied considerably. While the

health care workers' views were anchored by the institutional limitations currently experienced, the patients' outlook were considerably less constrained.

Medical participants reported that while the blanket rollout of a national electronic database containing codified medical information in a standard format would be the gold standard, resource constraints and the absence of a digital precedent in the state health care sector were thought to make this option untenable in the near-term. Keeping these landscape and institutional limitations, as well as their perceived understanding of patients' capacities for empowerment and responsibility, financial deprivation and lack of technological acumen as considerations, medical participants predominantly advocated the use of a summary format paper-based patient record to be implemented. Advantages proposed were the ease of use, compatibility within the existing physical ecosystems and workflow processes, as well as the presence of both informally used and established precedents. Together, these factors were reported to enhance the records potential for easy dissemination and implementation as it was an incremental improvement from the currently used system and could be used concurrently.

Implementation of a paper-based patient held record was reported by participants to possibly be aided by embedding institutional hooks within it to enhance its psychological value to patients.

We can also do away with the appointment cards and write them in the book. Because they hang onto these cards like they're gold. They don't help you unless you have the card. So I think that if you implement it with the appointment card people will look after it. That's the other problem I have because I run the INR clinic. When I give them the book, they don't give them back.

Doctor B

Attendance at the chronic disease club is dependent on patients presenting an appointment card, without which, they would have to wait in the longer general outpatient queue to be seen. Embedding this information into a novel patient held record could actively drive buy-in and establish its use. This can also prevent it from being discarded early on in its life-cycle.

Limitations of this format, as brought up by participants, relate to the value patients and doctors place in it. For medical staff, the accuracy, completeness and regularity of notes filled can increase or diminish its apparent utility and perceived worth. For patients, simple explanations of common medical conditions as well as documentation on their current disease status can assist in both educating them as well as providing a basis for communication with health care workers in future consultations. Prof H was of the opinion that unless these utilities were apparent to users, these books would not be taken up or looked after.

I think patients are concerned about their health, and you can show them the benefits about the system. I'm sure that a lot of them would take it up. Most people are worried about their health and how to live a better lifestyle. Patients don't know medical terminology and sometimes get confused. If you have accurate notation. So if the doctor can refer to this, then it would speed up the consultation, speed up getting the patient to hospital.

Prof H

Privacy concerns regarding paper-based patient held record were brought up by participants, especially with stigmatized diseases. Unsanctioned viewing of sensitive patient information in the home environment by family and friends was viewed by participants to possibly be a barrier to adoption of physical patient held records. Especially in the Langa area, where households can include 8 or more occupants.

Digitization of records was viewed with mixed feelings by medical participants, while patients enthusiastically proffered a wide variety of possible solutions. All of the solutions announced enabled patient control of their health records and advanced generalized sanctioned access, properties espoused to be important. These solutions included health records stored on flash-sticks, encrypted onto barcoded ID cards, cloud storage on cell-phone accessed web applications and access via unstructured supplementary service data (USSD).

When you put a card in the machine, a bank card, it brings up your information, you must put the pin in and it will bring up all your information. You understand, then it will give you access to your card. So that's what they should have here at the clinic, a machine that will bring up all the patients information, once they put the card into the machine, and punches that persons code in, it brings up all the information. It's as simple as that.

Vanessa

Barriers to the use of paper-based records are relatively limited as they easily slot into current workflow and behavioral patterns. However, adoption of the aforementioned digital format patient held records, while perhaps advantageous in many ways, could be constrained by a greater number of potential barriers. These barriers would result from their novelty and inherent incongruity with the technological ecosystem currently employed.

Prof H was of the opinion that with systems improvement, changes in efficiency and work process take place. Therefore, the balance between time and cost savings to affected parties have to be weighed up. He maintained that unless the benefits are apparent to doctors as well as patients, the additional work required for successful implementation would not be rendered.

If it were part of what they must complete at the end of each consultation, then it wouldn't be a barrier. Because they have to see a certain number of patients each day, and most of them are overworked and they going to try and save time on admin, so it has to be part of their record keeping. And not an extra.

Prof H

He also cited an example of the use of a hybrid system at Mitchells Plain District Hospital, which required employment of ancillary staff to scan paper records into a digital archive.

Besides workflow changes, participants cited infrastructural limitations to be a barrier to adoption of digital systems. Citing paucity of computers and slow internet connectivity at the site, the burden of additional electronic systems on the current infrastructure may not bode well for adoption unless the current system is replaced or significantly overhauled. Doctor E described that unless the facility had the means to access digital systems it ‘may just make you take longer’ to see patients.

The adoption of a novel system was noted by participants to be contingent on there being political and administrative motivation for change. Participants described that in the Department of Health’s clinics, there is a managerial unwillingness to implement change. Doctor B described that her attempts to advocate small systems changes were met with resistance.

The use of cellphones to access health records, while enabling generalized connectivity are limited to smart phone owners and those technologically literate and behaviorally willing to switch over to digital records. Participants described that the behavior change model required to implement a digital system in the current infrastructural ecosystem would be too much of a leap, suggesting that the time and resources needed would be better spent on primary patient education and health promotion.

4.2.6.1 Conclusion:

Health record innovation is required to realize currently unmet needs of patients and healthcare workers. Research findings suggest that a patient-held record format based on informally used ancillary antecedents would complement the currently prevailing technological ecosystem and diminish resistance to adoption. Digital derivatives, while enabling enhanced access may not be compatible with the demographic in question and could adversely affect work processes. Privacy and confidentiality of sensitive information is a concern and may be a barrier for those with stigmatized disease.

4.3 Discussion:

How does the experience of chronic disease patients with their health information inform the development of future health records in low income population groups?

This chapter will provide a discussion of the research findings, their significance within the clinical context of the study, as well as how they fit into and compare to previous research performed in this field. The primary and secondary research questions will be answered with evidence provided to support the researchers claims.

Exploration of patient and health care workers' experiences of medical records can inform their future development to enhance continuity of care.

4.3.1 Overview

Improvement of the health record to meet the unanswered needs of patients and doctors has to take workflow, institutional and cultural complexities into account as it plays a dynamic role within these interdependencies. Exploration of the experiences of doctors and chronic disease patients with their health information is well suited to unravelling these complexities. Research findings suggest that a patient-held record format based on informally used ancillary antecedents would complement the currently prevailing technological ecosystem and diminish resistance to adoption.

Health records at Vanguard Community Health Centre are exclusively paper-based, with consultation notes, results sheets, prescription charts and referral letters bundled into an A4 folder in a mostly unstructured manner. These descriptions are consistent with observations made by Mostert-Phillips et al. (2012). These records are based on and have not progressed far from those pioneered by the Mayo Clinic in the early 20th century. In fact, while the latter were called 'patient-centered clinical records,' current findings suggest that doctors pay more attention to these records than to the patients. This may be for a number of reasons, including the difficulty of making sense of the patient's clinical context when the notes are unordered, there is information missing and the patients themselves cannot give an adequate account of

their medical history. More recently, the fear of litigation has made clinicians increasingly circumspect about what they enter into the record.

Health records are a critical component of the clinics infrastructure and workflow organization. They are the primary source of patient information, documenting and communicating the health narrative over time for maintenance of long-term continuity of care. The process of documenting clinical information in the health record is an integral part of the clinic staff's workflow processes, institutionalized to the extent that doctors could not imagine working digitally. These findings are supported by Berg (1996) who suggests that writing is a key cognitive process involved in transforming patients' complaints into manageable conditions.

The versatility of written records as experienced by participants relates to the files' ability to connect disparate parts of the organization in a simple and relatively effortless manner, when they are available. In fact, findings have demonstrated that meaningful access to healthcare at the facility is dependent on patients accessing their folder, without which they cannot enter into the clinics' cycle of interactions. These findings are in keeping with the suggestions by Dick and Steen (1991) that records are no longer a 'repository of information' which represent reality, but rather, a factor which mediates the reality itself, and an active transformer "of the patient's body into an extension of the hospital's routine" (Berg, 1996). Improvement of the format of health records would have to account for and build in design functionality to deal with these multifarious needs. If they are not adequately addressed, they can impact on patients' access to care.

Unavailability of information at Vanguard Community Health Centre was frequently encountered and had a detrimental effect on continuity of care as well as the relationship between doctors and patients. Causes described included poor quality of note-taking, incoherent order with pages missing, or the loss of the entire folder. Folders were reported to have gone missing on a daily basis and duplicates were created. While this was reported to have occurred for a number of years, renovation of the archives at the clinic can partly explain some of the disruption in the storage and access to folders. It does however demonstrate a weakness of the paper-based system of record keeping. This break in the chain of continuity of care and the disruption of years' worth of documentary evidence resulted in wastage of patients and clinicians' time and resources. Baseline information has to be re-

established which is a difficult task as patients often do not know enough about their own health and disease profile to provide information for further safe management. Bricolage techniques are described by participants to deal with the loss of information, particularly medications and dosages. These techniques include the use of a medication board, which appeals to patient's visual memory rather than linguistic ability. If this proves to be inconclusive, patients are asked to return home to fetch their medication so that repeat orders can be prescribed. The results of this research support the idea that by themselves, the current paper-based system has shortcomings which contribute to poor patient care. These findings are borne out by previous research.

While versatile in performing multiple functions, inefficiencies related to storage, access, structure and content can play a role in diminishing the perceived quality of care and cause friction between patients and their health practitioners. While bricolage attempts to shore up the systems inadequacies are being made, limitations to the consultations therapeutic and educational potential have contributed to participants' feelings of frustration and anxiety. In fact, patients have expressed doubts in the quality of care being provided at the facility. This break in trust between the facility and patient population is concerning. The benefit of personal health records used in addition to the institutions own is backed up by findings by Coulter and Ellins (2007), who suggest that well-structured written information in addition to verbal advice can be used to improve patient knowledge, understanding and allay anxiety related to perceived severity of conditions and prognosis.

The results of this research support the idea that there is a discrepancy between patient needs and their fulfillment by doctors. The records' inability to portray information concisely results in doctors spending valuable time looking for information. This could be from the record or corroboration with the patient, leaving them little time to interact with patients, explore their current problems and understand their perspective. Findings suggest that patients are leaving the consultation without sufficient information to further their understanding of their conditions, or the confidence to question their management. There are a number of similarities between these findings and the published literature which suggests that health literacy includes the ability to communicate the needs of the individual with the health professional, understand and act upon written and verbal information. Seemingly, time spent providing patients with the education they require early on can yield benefits in their clinical course as patients are able to become equal partners in the healthcare relationship.

Interestingly, while admitting to not adequately address the educational needs of patients due to time constraints, doctors were critical of patients' lack of involvement and limited insight into their health. This is contradictory to findings by Ishikawa and Yano (2008) who argue that successful disease management is reliant on patient participation in the health care process. Similarly, a comparable study on caregiver and patient attitudes towards a personal health record in Lesotho showed that besides saving time for patients and doctors, they provided an opportunity for shared responsibility of care in an 'adult-adult' relationship (Henbest et al., 1995).

A consequence of poor patient literacy and unstructured medical records was the finding of inefficient consultations with participants citing the need to regularly re-establish basic information. Patients could not prepare for their consultations as they did not have physical material to ground their advancement nor the necessary skill or resources from which they could acquire educational material. This may be due to only 10% of households having internet access nationally (Statistics South Africa, 2013). As the consultation is the primary means of patient information acquisition, the complaint by patients of inadequate explanation in a manner that they can understand furthers the argument for the provision of hard copy health information. This is supported by findings in a study by Woods et al. (2013) which found that patient access to their records' contents improved their knowledge, preparation for consultations and confidence in communicating with providers. Furthermore, this is corroborated by a study performed by Huvila et al. (2015) who argues that access to their information can foster patient health information literacy for effective communication.

This study found that there were high levels of practitioner and patient dissatisfaction with the manner in which care was both provided and received. This is in part due to inefficiencies of the record and its effect on the efficiency of the consultation, differences in needs and expectations from the respective parties and the limited use of the consultation as a means of furthering patient literacy, empowerment and responsibility. Systemic reviews on the effect of patients' accessing their health information are inconclusive. So while access to information may further patient literacy and the potential to communicate with providers, as yet there is no substantive evidence supporting its effect on health outcomes and patient satisfaction.

A large part of the role played by health records in the primary care clinic is the provision of access to healthcare. Reports of patients' waiting for long periods of time and being forced to return home to fetch their medication if their records go missing were frequently encountered. Often, patients would have to return to the clinic on another date to see the doctor. Access to adequate emergency care and further disposition is also dependant on the folder being present. In light of these findings, the unanimity of patient expressions that access is more consequential than the potential for intrusion into their health information can be understood. These views were counterbalanced by those of the practitioners who felt that protection of patient information was of supreme importance. These expressions echo observations by Henbest et al. (1995) that practitioners were more likely to be concerned about confidentiality than patients themselves. The finding that patients place more importance on access to information over watertight privacy is significant when viewed together with the trust they demonstrated in the system's ability to protect personal information from unauthorised viewing. From the perspective of developing an improved format health record, these finding are reassuring- doubts and lack of trust are a potential source of resistance to uptake and have been demonstrated to lead patients to compromise their own health for the sake of protecting privacy and keeping their information out of an interoperable system.

A health record designed to meet the informational requirements of doctors, educational needs of patients and provide ubiquitous access can therefore improve the effectiveness of the consultation and transition it from a fact re-establishment exercise to one that creates shared responsibility and satisfaction for both parties.

Exploration of patient and health care workers' experiences of medical records has informed their development in a manner that addresses the needs of both parties for the successful design of a new format health record. This is important as co-creating the record in accordance with the needs of the end-user can prevent costly adoption failure.

These needs are:

1. Pervasive access to comprehensive health information accrued from all providers to maintain continuity of care and enhance the efficiency of the consultation.
2. Understandable health information for patients to use as a means of improving health literacy, communication skills and ameliorate anxiety.

Innovation of health records can be viewed within the complementary frameworks of technological transitions and diffusion of innovations theories. The design of a new format record to create pervasive access to health information to create continuity of care and health literacy for chronic disease sufferers from lower socio-economic populations would need to be in accordance with the principles advanced by these theories. This study has explored the cognitive routines and shared beliefs, capabilities and competences, lifestyles and user practices and institutional arrangements which together make up the status quo or regime rules by which actors co-ordinate activities to perpetuate the incumbent socio-technical system.

At Vanguard Community Health Centre and the surrounding network of public health facilities, paper-based records are the incumbent regime which has been embedded through long established structural, cultural and practical conglomeration. Breaking away or replacing this regime may prove to be difficult.

While there is a strong case for the implementation of health information technology, with the literature citing many benefits, including improved efficiency, productivity, positive health outcomes and the potential for nation-wide data capture, the current socio-technical environment may not be conducive to the dissemination of these digital formats. There are formidable barriers. These include the current health records role as a critical component of clinic infrastructure and workflow organization, paucity of supporting IT infrastructure, incompatibility with behavioural norms and importantly, limited resources for successful implementation. Political will in the form of the White Paper for the Transformation of the Health System's analysis and recommendation of the development of a National Health Information System (NHIS) is encouraging but may require persistence as benefits related to positive outcomes and cost saving only accrue following a lag period of increased expenditure.

Eighteen years after the initial deliberations on the implementation of electronic health records, their persistence demonstrates the power of regime lock-in. In order for innovations to gain purchase, reconfiguration of the linkages holding the incumbent regime in place needs to occur. Kemp, Scot and Hoogma (1998) comment that innovations would be valued and easily adopted, if they provide a good societal fit and incorporated within the established regime.

The move towards digitization may be aided by incremental change or the stretch-fit models of technological transition (Geels, 2005). These slowly transitioning models advocate conformation to existing regimes in both form and function with advancement guided by the user experience. This is in recognition of the important societal and cultural contributions necessary for its evolution.

Patient-held records informally used by patients from the Eastern Cape can provide the basis for health record innovation. They are acceptable to patients, positively viewed by practitioners and provide access to health information from multiple providers. There is also sufficient evidence from the literature supporting the use of patient held records. In addition, they conform to and are compatible with the existing paper-based regime of information capture and storage. As a backup device to the facilities' own record keeping practice, they can augment workflow process and ameliorate current inefficiencies to promote access, patient-centred continuity of care and health literacy.

4.4 Research limitations

Discussions of the findings have to be grounded in the limitations of the research approach and practical constraints.

The qualitative nature of the hermeneutic phenomenological methodology makes generated data subjective and open to varied interpretation and bias. The researcher has however maintained an audit trail for the evaluation of the studies rigor.

Participants were recruited from a single clinic and interviewed during a 2-month time period. Although thematic saturation was achieved, it is difficult to generalize these findings to the greater population.

A practical constraint of the research was its restriction to the chronic diseases club. Access to the experiences of patients attending the HIV and tuberculosis clubs at the clinic were therefore not obtained. Given the differences in disease profile, associated stigma and infective nature, their reality and potential needs may be different to those living with lifestyle related illnesses.

Language barriers made it difficult for Xhosa speaking participants such as Millicent and Nosipho to express themselves in a manner that yielded texturally rich data. Despite efforts made to keep the wording of questions simple to reduce misunderstanding, there is still the possibility that misunderstanding could have occurred.

5 Research conclusions

How does the experience of chronic disease patients with their health information inform the development of future health records in low income population groups?

This study was designed to explore the experiences of chronic disease patients with their health information in the context of the clinical environment for the purposes of gaining an understanding of the roles that they fulfill, their influence on the doctor-patient relationship and their impact on continuity of care. Findings of the study can be utilized to inform the future development of a contextually appropriate health record.

In comparison with the international move to digitize health information, records at Vanguard Community Health Centre are paper-based and stored within the facilities archives.

While lacking structure, this study shows that they are versatile in coordinating and documenting the patients' access to and interaction with healthcare services. They are relied upon for managing workflow processes at minimal cost in an environment characterized by resource and technological constraints. Furthermore, health information contained within the record communicates the summation of the patients' management from successive episodes of care and ground the consultation in the patients' contextual reality. Patients can have multiple medical records at separate health facilities, which can create a fragmented clinical picture.

Research shows that the presence, absence and quality of contents of medical records influences access to and the experience of care delivered in the therapeutic consultation. Patient education, understanding, and responsibility for their health contributes to the practitioner-patient experience. The importance of these findings underscores the observation that patients have poor levels of health literacy. In the absence of documented health information, patients are often unable to substantively communicate their medical history to practitioners for maintenance and progression of continuity of care, contributing to mismanagement and progression of disease.

Poor communication and the perceived lack of patient responsibility for their own care have created friction between doctors and patients with both parties expressing dissatisfaction with the delivery of healthcare services. Ineffective consultations arise which precludes health education and patient anxiety to be adequately addressed within the limited time of the formal consultation.

As the health record is a dynamic actor in the healthcare transaction and mediates the relationship between practitioner and patient, improvement in its design to meet the needs of these parties may improve patient literacy and enhance the therapeutic potential of the consultation.

The needs identified are:

1. Pervasive access to comprehensive health information accrued from all providers to maintain continuity of care and enhance the efficiency of the consultation.
2. Understandable health information for patients to use as a means of improving health literacy, communication skills and ameliorate anxiety.

The findings of this study support the idea that while paper-based health information records are versatile in performing multiple functions at the clinic, insights into the unmet needs of the end-user gained through phenomenological immersion advocate for their innovative development. A patient-held record based on ancillary antecedents such as the Eastern Cape health book, maternity case record and pediatric road to health chart was found to complement the incumbent technological regime and potentially diminish resistance to adoption.

As a cost-effective alternative to the prevailing trend towards digitization, this study finds that the development and implementation of a low technologically based personal health record used in addition to the facilities own records may adequately address the health needs of chronic disease sufferers from low income groups in Cape Town.

This study makes an original contribution to the existing body of knowledge by being the first to explore the everyday end-user experiences of paper-based health records in a Cape Town clinic.

6 Future research directions

These suggestions are offered to further explore the findings of this study for the future development of contextually appropriate health records.

1. Conduct a comparative study in the same or other primary care facilities with the inclusion of chronic infectious disease patients.
2. Extend the study to include multiple facilities, including inpatients at secondary and tertiary level hospitals.
3. Verify these findings using a quantitative research strategy.
4. Create and test a personal health record at the multiple facilities in the greater Cape Town peri-urban region.

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Appendix 1: Prototype and Business Plan



Problem Identification:

Health records play a fundamental role in storing clinical information, coordinating workflow processes within primary level clinics and communicating past management and future plans between practitioners and facilities. While the current paper-based folder system is simple, cost effective and versatile in fulfilling multiple roles, current literature as well as the researcher's phenomenological investigation of these records suggest that improvements can be made.

Shortcomings of these records relate to storage, retrieval and unnecessary duplication with consequent interruption in continuity of care. Their unstructured content makes it difficult for clinicians to gain a holistic understanding of their patients and their localization within the clinic precludes patients from coming to terms with their information at their own pace and in a manner that is comprehensible to them so that they can adequately communicate at future consultation.

Most importantly, is the potential to aid sub-optimally educated lower socio-economic chronic disease sufferers play a more active role in their own health, improve their health literacy and partner with the health establish to strengthen continuity of care

The development of a prototype to meet these goals was undertaken using the combination of phenomenological research as well as human-centered design principles.

Prototype development

Human-centered design for the development of 'people inspired innovation' involves 3 steps. These are discovery, ideation and prototype development (Ideo.org, 2013). Emersion and empathy building was achieved through the phenomenological process of eliciting experiences from the target population by means of dynamic conversations within the clinical environment. Ideation of the challenges experienced by the end-users, doctors and patients, was aided by coalescing and converging themes and insight statements from the interviews as well as the researchers personal observations at Vanguard Community Health Centre. The end point of the ideation phase led to the development of the problem-based solution orientated "How Might We" (HMW) question.

User Experience

Patient qualifies for record and demonstrates sufficient motivation for use

Access to record provided

Information populated by health care worker

Patients interact with their record out of the clinic

Patients bring record to follow-up appointments

Doctors update information

Prototype development

From the user experience and the HMW questions, the following prototypes were developed.

- Cellphone application
- USSD based cellphone messaging
- Paper-based personal health record

1. A cell phone application which is downloaded onto the patients feature or smart phone. Access is controlled by patients who can view their information, receive and read health promotion push message, and have reminders to take medication and attend follow up clinic visits.

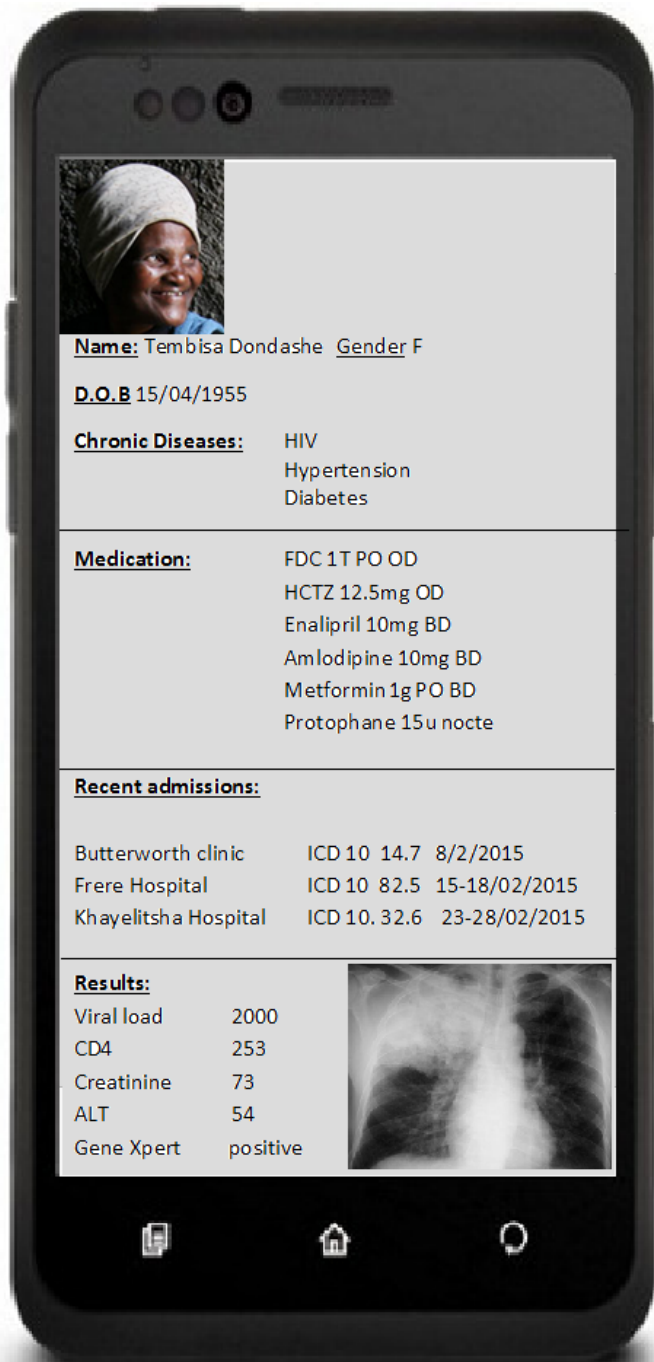


Figure 2 (top) and 3 (right). Cellphone application with doctor (2) and patient portals (3).



2. Unstructured Supplementary Service Data (USSD) accessed messenger service for convenient, national access to clinical information. This functionality can be used with older generation phones and requires minimal technological literacy.



Figure 4 USSD accessed messenger service

3. A paper-based patient held book formulated according to the principles of the maternity case record and pediatric road to health card which formalizes the socially accepted Eastern Cape health book.

My Health Passport

Name

Folder Number.....

D.O.B

 health

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Health
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Figure 5 Paper format personal health record

After conceptualization, these prototypes were taken to the clinic where the researcher facilitated feedback conversations with doctors and patients. The researcher provided multiple prototypes to the participants and created a neutral environment to stimulate honest and open discussion. In keeping with the principles of human-centered design, the researcher encouraged participants to adapt the prototypes and build on them in any way they felt would enhance the product to address their needs.

Feedback from the sessions were documented and applied to advancing the selection of prototype as well as features requires for success. From conversations with participants, it became increasingly apparent that while the cell-phone based derivatives provided greater functionality, the possibility of data capture for statistical purposes and the creation of a national health database, there were large obstacles to their adoption.

While the majority of patients carried cellphones of varied levels of advancement, they feared that they may be stolen which could result in them losing important clinical information. The possibility of cloud storage was not received with much enthusiasm. While doctors were impressed with the cellphone-based prototypes, they were concerned that they were contextually inappropriate and would unnecessarily lengthen consult times.

Overall, the participants agreed that a formalized version of the Eastern Cape book combined with features of the maternity case record and pediatric road to health chart would be an effective solution. Rapid prototyping of this concept through an iterative process of user engagement and prioritization of feedback led to the evolution of the content and structure of this patient-held book, called ‘My Health Passport.’

My Health Passport

This is a personal health record, which is supplementary to those used in private and public health institutions. It is meant to be used as an adjunct to address the unmet needs of the currently used institution-specific cardboard folder contained records. It fulfills the criteria of attributes of innovations, espoused by Rogers (1995), for successful adoption. This innovation has been co-created with the end-user by exploring their experiences of health records. There is a relative advantage to using this record in conjunction with currently used records. It is compatible with the prevailing institutionalized regime of paper-based records and complements current workflow processes. Furthermore, while the cellphone application and USSD service may be perceived to be relatively complex, this record builds upon a simple concept with a social precedent. As an innovation, it meets the needs of the target population, chronic disease sufferers from lower-socio-economic circumstances, as an incremental change, in a contextually appropriate manner.



Figure 6 My Health Passport front page

The front page contains the Department of Health’s logo (authorization still to be received) to establish legitimacy for the end-user. The naming of the book is purposeful- the use of the pronoun ‘my’ places ownership of the record in the hands of the patient and sets the precedent for a number of responsibility creating features built into the books’ format. The term ‘passport’ hints at the possibility of journeying towards a destination. These destinations are health literacy and continuity of care. Personal identification information links back to ownership established in the title. The advertising in the bottom right-hand corner will be covered in the business plan section.

Name..... Folder Number..... Date of birth.....		Operation..... Year..... Disability..... 1..... 2..... 3.....
Medical Conditions..... Year Diagnosed..... 1..... 2..... 3..... 4..... 5..... 6..... 7..... 8..... 9..... 10.....		Medication..... 1..... 2..... 3..... 4..... 5..... 6..... 7..... 8..... 9..... 10.....
Admissions..... 1..... 2..... 3..... 4..... 5..... 6..... 7..... 8..... 9..... 10.....		Date..... 1..... 2..... 3..... 4..... 5..... 6..... 7..... 8..... 9..... 10.....
Allergies..... 1..... 2..... 3..... 4..... 5..... 6..... 7..... 8..... 9..... 10.....		Department: Health REPUBLIC OF SOUTH AFRICA

Figure 7 Summary sheet

The summary sheet addresses the need of doctors to be able to establish basic information rapidly for an effective consultation to take place. It includes a list of the patients' chronic conditions, past medical history, allergies and medication.

Date	Clinic	Diagnosis with ICD 10 code
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		
9.		
10.		
11.		
12.		
13.		
14.		
15.		

Figure 7 Index of presentations.

The index of presentations, supplements the summary sheet so that the clinician can establish the current presentation within the context of previous episodes of health seeking behavior.

1/6/2014 cough / SOB
Scattered crackles
T 37.5°C
① CAP
② ART
③ Augmentin.

17/8/2014 cough / SOB
low
TB
① infection / TB
②

02/09/2014 weight +
① start TB treatment

05-10-2014 blood weight gain
increased appetite.
Chest X-ray clear.
Continue active phase treatment.
Follow up in 4 weeks

health
Department of Health
REPUBLIC OF SOUTH AFRICA

Figure 8 Continuation of care sheet

The continuation of care sheet briefly documents the patients' interaction multiple providers. This versatility allows the patient to move between health institutions in both the public and private sectors in different provinces, while maintaining continuity of care, without the need for referral letters. Healthcare workers can view previous interventions and management plans from other facilities in the case of referrals between institutions. In the scenario of a missing folder, the Health Passport can provide sufficient information for maintenance of the chain of continuity of care.

The image shows a rectangular form titled "My Health" in the top left corner. A vertical line runs down the left side of the form, and horizontal dotted lines are spaced evenly across the page, creating a grid-like structure for writing.

Figure 9 Patient health diary

The health diary actualizes the shift of responsibility from the health practitioner to the patient in the creation of the health partnership. The process of writing down symptoms and concerns can promote patient introspection of disease, prepare them for the consultation and speak on their behalf if they cannot remember or are anxious to report somatic complaints. For the healthcare providers, the diary can provide an insight into the patients' perspective, level of understanding, fears which need to be allayed, as well as time course and complexity of symptoms. Together, this may enhance the efficacy and therapeutic capacity of the consultation.

A glossary of medical terms can improve patients' vocabulary so that they can understand explanations given to them, thereby becoming health literate.

Prototype testing

Testing of the prototype took place in 3 phases

1. Conceptualization: from the application of phenomenological and human centered design principles.
2. Refinement: An iterative process of refinement of the prototype with demonstration to the end-users.
3. Clinical pilot.

The brainstorming and development of the first 2 processes are described in the previous sections. The in-context clinical pilot took place at Vanguard Community Health Centre after a lengthy period of refinement and gaining feedback on previous iterations from the participants.

Experimental designs

The third phase of testing the prototype took place during patient consultations in two parts:

1. Qualitative interviews:

Methods: 3 sets of interviews took place with both doctors and patients present. The 'My Health Passport' personal health record was presented to the participants. A brief background to the prototype was given which included sufficient information to contextualize the record without influencing participant opinions.

Sampling: non-probability convenience sampling.

Sample size: 6

Data generation: qualitative interviews

Findings: The health passport was viewed favorably by 5 of the participants who were keen to use it. They were of the opinion that the record would be able to assist the consultation as it summarized the patients' history and allowed entries from multiple providers. Patients described that they would no longer have to try and remember

Sample size: 5

Control: The physicians themselves

Data generation: post-intervention qualitative interviews

Findings: The respondents were overwhelmingly positive in their appraisal of the summary sheet from the My Health Record.

“It makes a huge difference and brings up all the relevant point.” Doctor T

“Makes things easier as you don’t have to sift through the folder.” Doctor C

Participants expressed that the summary sheet provided sufficient information for them to gain an understanding of the patient so that they could progress to a systemic inquiry. One participant responded that it would assist her in viewing information from external sources as well from her colleagues’ notes in the file. Participants were however concerned that the record may be misleading if inputs were omitted, not adequately completed, suggesting that its utility was only valuable as the quality and consistency of documentation.

Discussion: The summary of care sheet was positively viewed by participants to promote continuity of care and to lead to more efficient consultations. Concerns over the accuracy of the record was brought up in the case of incomplete documentation. This is however a drawback common to all health records. The use of the participants themselves as controls was required as the quantification of the effectiveness of a consultation is fraught with ambiguity. Furthermore, quantitative use of consultation length as a marker for efficiency belies the diversity and complexities inherent in the makeup of the consultation. While there are drawback to the use of qualitative methods in this quasi-experimental design, accord with previous research performed at the clinic is reassuring. While the test is limited in its scope, it does however provide an indication of the perceived utility of a component of this personal health record.

My Health Passport

Business Plan

My Health Passport is a collaboratively created personal health record for lower socio-economic chronic disease sufferers in the Cape Town peri-urban area. With initial funding from Health Care Works (Pty) Ltd, these records will be available for eligible patients free of charge. We plan on distributing the first 1000 copies by March 2017 ,with the expectation of receiving further grant and corporate social responsibility funding for expansion of the project thereafter. We will keep costs to a minimum by utilizing existing networks and value chains for the distribution and promotion of the product.

Vision

Within 5 years, build My Health Passport into a nationally recognized personal health record that supports the development of health literacy and continuity of care for lower socio-economic chronic disease sufferers in South Africa through the development of partnerships with communities, non-profit organizations and local government departments.

Mission Statement

Enhancing healthcare

Value proposition

We empower chronic disease sufferers attain health literacy and continuity of care through a free for public sector use personal health record.

Objectives and Impact

- Attain Department of Health or City of Cape Town endorsement by December 2016
- Develop partnerships with 3 non-profit organizations by March 2017
- distribute 1000 My Health Passports by March 2017
- increase the number of passports from 1000 to 5000 by June 2017
- Increase funding from R15 000 to R45 000 by June 2017
- Increase operating sites from 1 to 3 by June 2017
- On-going evaluation and improvement of patient health literacy

Strategies

- Register as a non-profit organization.
- Become nationally known for creating and distributing contextually appropriate personal health records.
- Focus on serving chronic disease sufferers in lower socio-economic communities.
- Core offering is a personal health record.
- Generate first time donations by partnering with Health Care Works (Pty) Ltd.
- Generate revenues by applying for grant and corporate social responsibility funding.
- Use strategic alliance with non-profit organizations and local government departments to expand base of operations.
- Assure funds are spent wisely by being volunteer driven and negotiating the purchase of materials.
- Attract industry experts to be board members.

Management

Dr Yusuf Parak is the founder and currently the sole member in the My Health Passport non-profit organization. He has 11 years of experience studying and working in various positions within Western Cape public health sector. In addition, he is a director and shareholder in

Health Care Works (Pty) Ltd, a for-profit company which facilitates short-term medical employment by means of an online platform. Dr Parak has developed and continues to maintain an extensive professional network within the medical and health technology industries. His influence within these networks will be leveraged to garner support for the successful implementation and dissemination of My Health Passport personal health record.

Market opportunity

The South African Health Review of 2013/2014 statistics demonstrate that chronic diseases of lifestyle affect 20.5% of the national population. Changes in lifestyle patterns has resulted in non-communicable disease becoming increasingly prevalent, with the urban poor and people over 65 most affected (Mayosi & Benatar, 2014). A further 8.2% of the population are infected with HIV (Health Systems Trust, 2014). With the rollout of antiretroviral medication and the resultant reduction in mortality, HIV has been transformed into a chronic disease (Mayosi & Benatar, 2014). Based on a population size of 52 million, this equates to 15.6 million chronic disease sufferers in South Africa.

Market Demand

While the potential market size is significant, the demand for personal health records in the South African context has not been fully delineated. In fact, exposure to personal health records has not been prevalent until the insurance and financial services company, Discovery, launched HealthID in 2012 (Erasmus, 2014). In a study exploring patient attitudes towards personal health records conducted in the Eastern Cape by Pottas & Mostert-Phipps, (2013), 90% of participants expressed the importance of providers having full access to their records. However, 69% did not store medical records in any form. Promisingly though, a strong predictor for keeping personal medical records, which were mostly paper-based, was the existence of a chronic medical condition. Local findings at Vanguard Community Health Centre by the researcher have indicated participant enthusiasm for personal health records to meet yet unanswered needs. Therefore, while the use of personal health records are still in their infancy in South Africa, there is some potential for a paper-based derivative.

Market segmentation

My Health Record's focus is on providing personal health records to lower socio-economic chronic disease sufferers who attend primary care facilities in the public health sector. While the records are tailor made for the peri-urban health user in the Western Cape, further research is required to assess the feasibility of providing them to private care institutions and the general public for a nominal price.

Competition

Electronic personal health records have been available to middle-class policy-holders via their medical aid since 2012 with offerings by Discovery and Metropolitan Health. Furthermore, Healthspace (Pty) Ltd offers an electronic patient portal available to the general public, which had attracted 946 users by 2014 (Erasmus, 2014). However, Healthspace is unlikely to be targeted at lower income users due to limited availability of internet access in poorer communities. There are currently no officially authorised paper-based personal health records in the Western Cape for adult chronic disease sufferers. However, indirect competition can come from the informal use of lever-arch files or lined books acquired from the stationery aisle by a sufficiently motivated individual.

Marketing Strategy

Product:

My Health Passport was developed through extensive research of the needs and preferences of the end-user. Phenomenological as well as human-centered design methodologies were applied in the co-creation of a product that is finely attuned to the nuances of the local health context. As an incremental change rather than disruptive innovation, the product complements rather than supplants the current paper-based hospital located record system. The product was designed to improve patient health literacy and involvement in their care. Attention to workflow processes and systems management influenced the design to create more efficient patient consultations. The developer envisions that enhancing the healthcare experience for both patients and doctors will facilitate the adoption and dissemination of the product so that scale can be achieved.

Place:

The product will be distributed from chronic care clubs in public sector primary care facilities. Initially, delivery to the facilities will be performed by Dr Parak. Depending on the uptake and demand from regional and distant clinics, arrangements will be made with DSV Healthcare who is contracted to distribute pre-packaged chronic medication in the Western Cape. Patients will be selected based on the applicability to their clinical conditions and potential to benefit from the innovation. Selection will be done at the discretion of the attending health worker with the go-ahead of the patient. A patient sticker with contact details will be placed in a register for record keeping and feedback purposes. Additionally, a My Health Passport sticker will be placed on the patients folder so that health workers attending to the patient at future consultations can be aware that a personal record can be viewed in conjunction with the existing record.

Price:

The production cost of the My Health Book will be from R12 -R15 individually in a batch of 1000. This is the main cost driver as distribution will be via the clinics staff and there are no salaries to pay. The cost of the first batch will be borne by Health Care Works (Pty) Ltd after which further grants will have to be sought. Funders will have their contributions acknowledged by means of 3cm x 3cm logo placement on the front cover. As both patients and doctors will view this health record, we assume the branding rights to be of moderate value, while still sourced from a corporate social responsibility (CSR) budget.

Promotion:

Endorsement of the personal health record by the Western Cape Department of Health, City of Cape Town health sub district office, NGO's or academic institutions who run primary care clinics is imperative for the early roll-out of the My Health Passport. Without official buy-in, distribution of the book will not take place. For the short-term, attaining this endorsement is imperative. Thereafter, facilitating discussions one-on-one or group discussions with facility managers and health workers will take place as they will be at the forefront of selecting candidates, populating baseline information and motivating patients to the book.

Operational Plan

Product supply and purchasing

Printing of My Health Passport will be outsourced to a local press, of which there are many in Cape Town and surrounds. Current quotations are in the range of R 12- R 15 for 1000 books. The developer is in discussions to get a discounted rate.

Research & Development

Significant research has gone into the development of My Health Passport up to this point. With the distribution of the first 1000 records into the community, Dr Parak will capture the details of recipients. Further research will be undertaken on the uptake, perceptions and experiences of the end-user as well as quantifying the potential for improvement of health literacy using the REALM or TOFHLA score (Nutbeam, 2008). As these tests take 22 minutes to administer, they will not be performed at selection as it may pose as a barrier. Findings will be used to make improvements to later editions of the product.

Systems support

My Health Passport will initially be launched at Vanguard Community Health Centre. A pre-launch meeting will be arranged with the medical manager and doctors to formalize the standard operating procedure for selection of candidates and distribution of the health records. Their buy-in is key to the successful running of this project. Thereafter, all queries will be directed to Dr Parak via the facility manager.

Key Partnerships

Access to facilities is dependent on authorization from the relevant health authorities. The City of Cape Town, Department of Health as well as the University of Cape Town's SHAWCO (Student Health And Welfare Centres Organization) and Stellenbosch University's MGD (Matie Gemeenskapsdiens) run primary care facilities in the greater Cape Metropole.

Depending on the demand from other facilities, DSV Logistics will be approached to assist with the distribution of booklets.

Funding

My Health Passport has received a commitment from Health Care Work (Pty) Ltd to cover the printing costs for the first batch of 1000 books. Thereafter, the company may continue to support the My Health Passport, however this is not guaranteed. Alternative streams of donor funding will be sought from within the medical industry, established corporate social responsibility campaigns and crowd funding platforms such as Thundafund.

Risk management plan

External risks:

Macro-environment:

Social unrest in the peri-election period may occur, combined with the risk of violent crime in the Cape Flat areas may hamper distribution of My Health Passport. These risks may be mitigated by exploring alternative distribution channels or communicating with the local branch of the South African Police Force (SAPS) prior to delivery.

Micro-environment:

Access:

Local government departments and academic institutions may not be willing to partner with My Health Passport for involvement at their sites. While the impact of this is high, based on current feedback, the likelihood of occurrence is low. However, steps to mitigate this threat include demonstration of the product to multiple organizations. While it is envisaged that the initial phase of distribution will take place at a single facility, having secondary options may be prudent.

Market demand:

Demand for personal health records from patients may not be in line with expectations, or there may be insufficient support and enthusiasm from clinicians to select eligible candidates for My Health Passport. The likelihood of the occurrence is low as the product has been co-create in this community with their feedback taken into consideration at every step of development.

Internal risks:

Storage of My Health Passport:

Loss of My Health Passport arising from theft or misplacement is a strong possibility. This will have to be guarded against by adequately assessing storage agreements with facility management prior to delivery.

Human resources:

My Health Passport currently only has one member, the founder. This limits the possibility of networking, shared responsibilities and collaborative creative insight. The founder will mitigate this by searching for and recruiting board members on a voluntary basis to assist in advisory and research roles.

Appendix 2: Ethics Approval

FULL COLOUR THINKING



Dr Stephanie Giamporcaro
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GSB/COM/015

Cape Town, 18 June 2015

Yusuf Parak

University of Cape Town, Graduate School of Business

parak.yusuf@gmail.com

Dear Yusuf

Re: Ethics Approval

Thank you for submitting your ethical clearance application for your research on **"Personal health records for chronic diseases in South Africa"**.

This is to confirm that your application has been assessed by the GSB's Ethics in Research Committee according to the rules and norms of the University and Commerce Faculty, and that it has been approved.

Please note that if you make any substantial change in your research procedure that could affect the experiences of the participants, you must submit a revised protocol to the Committee for approval.

We wish you all the best for your research.

Kind Regards

Signed by candidate

Dr Stephanie Giamporcaro

Research Director

FULL COLOUR THINKING



Appendix 3: COREQ Principles

Table 1 Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>
3.	Occupation	What was their occupation at the time of the study?
4.	Gender	Was the researcher male or female?
5.	Experience and training	What experience or training did the researcher have?
Relationship with participants		
6.	Relationship established	Was a relationship established prior to study commencement?
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>
Domain 2: study design		
Theoretical framework		
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>
Participant selection		
10.	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>
11.	Method of approach	How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>
12.	Sample size	How many participants were in the study?
13.	Non-participation	How many people refused to participate or dropped out? Reasons?
Setting		
14.	Setting of data collection	Where was the data collected? <i>e.g. home, clinic, workplace</i>
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?
16.	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>
Data collection		
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?
20.	Field notes	Were field notes made during and/or after the interview or focus group?
21.	Duration	What was the duration of the interviews or focus group?
22.	Data saturation	Was data saturation discussed?
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?
Domain 3: analysis and findings		
Data analysis		
24.	Number of data coders	How many data coders coded the data?
25.	Description of the coding tree	Did authors provide a description of the coding tree?
26.	Derivation of themes	Were themes identified in advance or derived from the data?
27.	Software	What software, if applicable, was used to manage the data?
28.	Participant checking	Did participants provide feedback on the findings?
Reporting		
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? <i>e.g. participant number</i>
30.	Data and findings consistent	Was there consistency between the data presented and the findings?
31.	Clarity of major themes	Were major themes clearly presented in the findings?
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?